

Family Caregivers of Individuals with Intellectual Disability: Perspectives on Life Quality and the Role of Vacations

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Existing literature on quality of life (QOL) among individuals with intellectual disability and their families is largely etic in nature and, although leisure is often advanced as a core contributor, the role vacations play has not been directly examined. Drawn from phase one results of a larger, multi-year study, our purpose in this paper is to highlight the perspectives of family caregivers (i.e., biological and adoptive parents, and adult siblings) of individuals with intellectual disability on the meaning of QOL and the influence of vacation behaviour in its construction. Data collection was done via focus groups, while a grounded theory approach was employed as the analytical framework. For the participants in this study, personal health and basic need fulfillment were foundational elements, with QOL being a much broader and encompassing concept that integrates meaningful and enriching social connections with friends and family, and perceived control, freedom and independence. Financial resources, quality respite, and health and impairment concerns specific to the family member with a disability also were key factors that had the capacity to facilitate or constrain life quality. Respite and health/impairment issues also demonstrate how caregivers' personal perspectives about QOL often meld with concerns affecting other family members—hence blurring the distinction between individual and family conceptions of life quality. Revealed as unique to this research and population group, are the complex features of family vacations that involve

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a child with intellectual disability (e.g., “outsiders” on vacations), which illustrate how typical and atypical costs and benefits of vacationing are magnified.

KEYWORDS: *Quality of life, intellectual disability, family caregiving, vacation, leisure.*

Introduction

Quality of life (QOL) is difficult to define, conceptually, and a challenge to measure methodologically (Kovac, 2004; Raphael, 1996; Veenhoven, 2000). Despite these difficulties, contemporary definitions converge on QOL as a socially constructed and multidimensional construct that subsumes a number of related factors (e.g., life satisfaction, happiness) (Schalock, 2000; Schalock, et al., 2002). Leisure, generally, and vacations, specifically, are often identified as positive contributors to, and essential elements of life quality (Gilbert & Abdullah, 2004; Heyne, Schleien, & Rynders, 1997; Mannell & Kleiber, 1997). Within leisure studies, life quality is an embedded, yet not always directly articulated, focus of inquiry. For example, the role of leisure in individual conceptions of life satisfaction, health, and personal growth and its collective contributions to family cohesion, marital stability, and satisfaction with family life are common areas of interest (Horna, 1989; Hendry, Shucksmith, Love, & Glendinning, 1993; Mactavish & Schleien, 2004). Vacation as a means of physical and psychological recovery from the rigours of work and daily living, also is well documented (Gump & Matthews, 2000; Strauss-Blausche, Muhry, Lehofer, Moser, & Marktl, 2004; Westman & Eden, 1997). Traditionally, much of this work has been driven by dominant societal views (white, Euro-centric, middle class), which has neglected, among many other people and issues, the interests and needs of individuals with intellectual disability,¹ and their families (Mactavish & Schleien 2004; Shaw & Dawson, 1998).

Results from an emerging area of leisure research that focus on these individuals and their families, indicate that family recreation is an important, albeit not always positive, context for promoting a host of personal and collective benefits (e.g., family unity, bonding, skill development) and buffering negative external influences (e.g., negative public attitudes, social exclusion; Mactavish & Schleien, 1998; 2004). Among the various forms and patterns of family and individual leisure, vacations—holidays taken by the family as a whole or smaller sub-groupings within the family—offer a unique and intensive microcosm for further study.

This notion was the rationale for one aspect of a three year, multi-phase initiative that addresses a broad range of questions including the symbolic

¹ Intellectual disability, also known in some parts of the world as mental retardation (USA) or learning disability (UK), is a lifelong disability that originates before age 18 and is characterized by significant limitations in both intellectual functioning and adaptive behaviour (i.e., as expressed in conceptual, social, and practical adaptive skills) (American Association on Mental Retardation, 2002).

and instrumental meaning of leisure (generally and vacations specifically) and its relationship with life quality, and the interaction/influence of individual, family, and external factors in informing this relationship. The overarching purpose of the larger initiative from which the reported results are drawn, is to develop a holistic and theoretically grounded understanding of QOL that is derived from individual and family perspectives, and identifies possible links with extant knowledge about QOL and related areas (e.g., family adaptation, leisure).

The purpose of this paper is to chronicle initial findings specific to the perspectives of family caregivers (i.e., biological and adoptive parents, and adult sibling) of individuals with intellectual disability on the meaning of QOL and the role various patterns of leisure, as exemplified by vacation behaviour, play in its construction. In adopting this focus, our intention is not to suggest that families that include members with an intellectual disability inherently differ from other families (especially those in which children are being raised), but to acknowledge the unique and often extended nature of caregiving responsibilities in these contexts and to facilitate better understanding (Blacher, Baker, & Braddock, 2002; Poston, et al., 2003; Summers, et al., 2005). Additionally, it is important to recognize that the reported findings are products of the first phase of a multi-year project and will be the basis for subsequent study. Our aim in this paper, therefore, is not to be definitive or exhaustive but to provide a foundation for directly exploring the interconnections between quality of life, leisure, and vacations—which have not been explicitly articulated or examined previously. This approach is consistent with, and substantiated by, recent calls in the disability literature for a shift from indicator or domain specific assessments of quality of life to one that considers the experiences and contexts (e.g., leisure) that reflect the full and interconnected nature of people's lives (Verdugo, Schalock, Keith, & Stancliffe, 2005).

Related Literature Review

Empirical and theoretical knowledge from a number of traditionally discrete sources are linked in this review to provide an integrated overview of the grounding for this paper. Namely the review addresses: QOL research specific to individuals with intellectual disability and their families (e.g., issues in conceptualization, measurement, conceptual frameworks); travel motivation theories; vacation behaviour and QOL; and vacation travel for persons with disabilities.

Research on Quality of Life

Among researchers interested in individuals with intellectual disability, QOL has been a central interest over the past 10 years (Seltzer & Krauss, 2001). While enhancing understanding about the life quality of these individuals is an implicit aim, most existing research is *etic* in nature and em-

phasizes issues in service development, delivery, and evaluation. In particular, researcher driven interests in defining QOL and methods of measurement that conform to psychometric standards (e.g., reliability, validity, standardization) have been major preoccupations (Cummins, 2005; Verdugo, et al., 2005).

The difficulties of defining QOL are evident in the myriad of terms (e.g., life satisfaction, happiness, well-being) that are used inconsistently and, at times, interchangeably in the literature (Veenhoven, 2000). Some researchers view these concepts as distinct, with happiness being related to transient affective states, life satisfaction referring to how well life's expectations are being met, well-being pertaining to more global expressions of satisfaction with the nature of one's life, and QOL being an even broader concept (Deiner, 2000). Others continue to question how these concepts relate to one another, while still others ask whether such distinctions are meaningful. For example, some researchers argue that happiness or, more specifically, a person's disposition towards happiness is the best predictor of well-being (Helm, 2000). Another perspective is that satisfaction is most salient to life quality, while others contend that this relationship is mediated by the importance or value people attribute to various aspects of life (Cummins, 1995; Felce & Perry, 1995). As researchers wrestle with these issues, QOL continues to lack a precise or consistently applied definition (Brantley, Hubner, & Nagle, 2002).

Studying methods of measurement also has been popular in this area. Despite early recognition that QOL is subject to individual interpretation (Edgerton, 1975; 1990), which would lend itself to naturalistic forms of inquiry, most of this research is grounded in tenets of (post-) positivism (Raphael, 1996). A number of measurement strategies have resulted, some of which incorporated the perspectives of individuals with disabilities and their families (Renwick & Brown, 1996) in their development, but more commonly rely on information provided by service providers or researchers' judgments (Heal & Sigelman, 1990; Seltzer & Krauss, 2001; Verdugo, et al., 2005). These approaches are usually dichotomized as (a) functional methods (e.g., rating scales) for assessing objective indicators (e.g., health), or (b) self-appraisal strategies (e.g., questionnaires) for evaluating subjective indicators (e.g., life satisfaction) (Schalock, 1996). At one time it was common for researchers to focus on either subjective or objective indicators of life quality. While some maintain the appropriateness of this approach (Hatton, 1998), most advocate a combination of the two and the use of multiple methods (Cummins, 1997; 2005; Raphael, Brown, Renwick, & Rootman, 1996; Schalock, et al., 2002). One rationale for this position is that research "has cast doubt on the power of objective variables alone, especially in view of what has been termed the paradox of well-being" (the presence of subjective well-being in the face of objective difficulties that would be expected to dictate otherwise) (Bowling & Windsor, 2001, p. 57). Other researchers are highly critical of any approach to assessing/measuring QOL that is not based on the expressed views and interests of individuals with intellectual disability

and their families. Advocates of this perspective charge that to do otherwise exposes people with intellectual disability to the risk of further marginalization by imposing external conceptualizations and judgments about the quality of their lives (Taylor & Bogdan, 1990; Wolfensberger, 1994).

While these definitional and methodological challenges are not fully resolved, contemporary literature converges on the view that QOL is a multidimensional, socially constructed concept that incorporates a number of related constructs (e.g., satisfaction, happiness) that may vary according to life stages and circumstances (Schalock, et al., 2002). A number of conceptual models have been advanced, each organized in different ways but including very similar core components, to depict the dimensions or conditions that contribute to *individual* life quality (Felce, 1997; Verdugo, et al., 2005). Schalock's (2000) model, one of the most commonly cited, is composed of eight core dimensions and related indicators: (a) emotional well-being (safety, happiness, freedom from stress); (b) interpersonal relations (e.g., intimacy, family interactions, friendships, social supports); (c) material well-being (e.g., financial security, food, possessions, employment); (d) personal development (e.g., education, skills, personal competence, purposeful activity); (e) physical well-being (health, nutrition, leisure, activities of daily living); (f) self-determination (e.g., autonomy, decision-making, personal goals/values); (g) social inclusion (e.g., acceptance, community integration/participation), and; (h) rights (e.g., privacy, access, due process, civic responsibilities).

While recognizing the importance of focusing on core elements of *individual* life quality, concerns have been expressed that this has limited understanding about QOL in family contexts (Brown, Anand, Fung, Isaacs, & Baum, 2003; Poston, et al., 2003; Rapley, 2003; Seltzer & Krauss, 2001; Summers, et al., 2005). This is an important concern as research in other areas (e.g., social support) indicates: (a) the pivotal and enduring role (positive/negative) of families in the lives of individuals with intellectual disability (Blacher et al., 2002), (b) the increasing emphasis on family-centered services that acknowledge family strengths, decision-making capacity, and promote family as the primary unit of support (Dunst, Johnson, Trivette, & Hamby, 1991; Turnbull, Turbiville, & Turnbull, 2000), and (c) that individuals and families do not always agree about the value or role of core elements (e.g., social integration, leisure) in existing conceptualizations of QOL (Mahon, Mactavish, & Bockstael, 2000; Perry & Felce, 2002; Stancliffe, 2000).

Turnbull and her colleagues (Turnbull, Brown, & Turnbull, 2004) recently proposed a 10-dimension (daily family life, family interaction, financial well-being, parenting, advocacy, health, productivity, emotional well-being, physical environment, social well-being) conceptual framework of *family* life quality. Building on this model, Poston et al. (2003) dichotomized the 10 domains of family quality of life into two orientations—individual and family. Factors specific to the individual (i.e., individual orientation) include six dimensions (i.e., advocacy, health, productivity, emotional well-being, physical environment, and social well-being), which in the context of one's life

experiences are idiosyncratically configured to produce personal variations in QOL. Domains within the family orientation—daily family life, family interactions, financial well-being, and parenting—are advanced as the contexts for interaction and infusion of individually oriented factors into collective or family constructions of life quality. This model, like much of the emerging family QOL research, is grounded in systems theory (Schalock, 2005), which contrasts the predominantly atheoretical nature of individual models (Parmenter & Donnelly, 1997). From this theoretical perspective, family is viewed as a dynamic social system that influences and is influenced by its individual members and their interactions (Turnbull & Turnbull, 1990; Summers, et al., 2005). These interactions, which are affected by characteristics of the system (e.g., family structures), create stresses that affect adaptation, cohesion and family functioning (i.e., the activities family undertake to meet individual and collective needs).

Researchers in family adaptation, which is related to QOL but often addressed as a distinct issue, advocate a social ecological approach to accommodate the inter-play between larger macrosystems (social, economic, and political influences) and family microsystems (Bronfenbrenner, 1979; White & Klein, 2002). One of the difficulties with this approach is identifying and isolating factors relevant to understanding family adaptation. Ecocultural niche theory, which brings together tenets of ecological and cultural theory, has been advanced in the disability literature as a way of addressing this concern (Gallimore, Coots, Weisner, Garnier, & Guthrie; 1996; Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Summers et al., 2005). This approach involves studying the routines and daily activities of families that include a member with a disability as they are considered the “crucible within which a multiplicity of influences is forged into a family’s adaptations to the hassles of daily life” (Ferguson, 2001, p. 388). More specifically, within ecocultural theory the construction and maintenance of daily routine is not only a mechanism for coherent family adaptation, but also a context for “development-sensitive” (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993, p. 186) opportunities that promote child growth and learning.

Conceptual Models of Travel Motivation

The motives that inspire individuals to travel have been a popular subject of interest for a number of years. Over 25 years ago, Crompton (1979), in his seminal research on pleasure travel motivation, identified seven socio-psychological and two cultural motives. The former included (a) escape from a perceived mundane environment, (b) exploration and evaluation of self, (c) relaxation, (d) prestige, (e) regression, (f) enhancement of kinship relationships, (g) and facilitation of social interaction. The latter (i.e., cultural motives) were (a) novelty and (b) education seeking. Socio-psychological motives drive the impetus for travel, while cultural motives reflect the influence of the destination in further arousing travel desire through its uniqueness and/or learning opportunities. Iso-Ahola (1983) also offered a classic

dialectic motivation model, which illustrates how seeking personal and interpersonal rewards and escaping personal and interpersonal environments drive leisure and tourism behaviour. Pleasure travel, specifically, was credited with exaggerating the leisure benefits associated with anticipation and recollection of events and enhanced perceived well-being pre- and post-vacation (Gilbert & Abdullah, 2004). Contemporary research shows that tourists continue to echo reasons for travel that are consistent with these early conceptualizations. For example visiting friends and relatives, sharing family time, feeling at home away from home, relaxing, having fun and being entertained are commonly cited motives (Echtner & Ritchie, 1993; MacKay, Andereck, & Vogt, 2002).

Vacations and Quality of Life

Engaging in memorable and meaningful experiences, such as vacations, rather than consuming material goods was recognized recently as important indicators of QOL (Oppermann & Cooper, 1999; Richards, 1999). This material-to-experience shift in consumption habits is underscored by the contention that tourism is income inelastic—that is, a reduction in personal income or an increase in tourism services pricing, does not decrease demand proportionately (Ryan, 2003). While linked to individual QOL as a vehicle for enhancing social interaction, personal development, pursuit of interests, and identity formation, pleasure travel is rarely incorporated as a direct area of focus in life quality research. One reason for this limited attention is that vacations are frequently viewed as distinct from the pace and rhythm of daily living and, as such, less germane to broad-based conceptualizations of life quality. Substantiating this view, Richards' (1999) noted, "holidays offer relief from time and place, two of the key constraints of everyday life" (p. 189).

Similarly, while enhancing family relationships is a well-documented travel motive, researchers interested in family vacation behaviour have paid greater attention to travel decision-making processes than they have to the role of vacations in QOL (Jo, Kosciulek, Huh, & Holecek, 2004; Kang & Hsu, 2005; Madrigal, 1993; Seaton & Tagg, 1995; Thornton, Shaw & Williams, 1997; Wang Hsieh, Yeh, & Tsai, 2004). As a more complex process than individual travel decision-making, the roles of family members and/or stage of family life cycle have been used as the main theoretical approaches to understanding family travel patterns (Fodness, 1992; Hill, McDonald & Uysal, 1990; Oppermann, 1995; Seaton & Tagg, 1995). Relative influences and roles of family members are found to vary based on type of purchase decision, stage in decision-making process, and family characteristics (Wang et al., 2004). There is general agreement that vacation decisions are made jointly by spouses, however, the degree of influence held by children has been less conclusive and typically linked to age (i.e., older children participate more in the decision-making vs. younger children influence parental choices more; Madrigal; Seaton & Tagg). Seaton and Tagg's research also revealed that involving children in the vacation decision-making process en-

hanced the prospect of positive outcomes (i.e., satisfaction). Recent evidence, however, suggests that the changing nature of family roles and composition may make earlier work in this area less relevant to current vacation decisions (Gardyn, 2001; Kang & Hsu, 2005).

Pleasure Travel and Persons with Disabilities

Research on the vacation behaviour of people with disabilities is almost non-existent and what is available is relatively recent and exclusively focused on travelers with physical disabilities (Burnett & Baker, 2001; Daniels, Drogin-Rogers, & Wiggins, in press; Israeli, 2002; McKercher, Packer, Yau, & Lam, 2003; Ray & Ryder, 2003; Shaw & Cole, 2004). Much of this literature addresses structural accessibility (Israeli, 2002) and constraints issues (McKercher et al; Ray & Ryder, 2003). As a result it is generally recognized that while most pleasure travelers encounter constraints to their vacation behaviour, travelers with a disability face magnified and unique constraints. Notable exceptions to the singular focus on environmental accessibility includes the interpretive work of Daniels et al. (in press), which considers other forms of constraints (i.e., intrapersonal, interpersonal) and gives voice to travelers with physical disabilities through an analysis of narratives of their travel experiences. In addition, Shaw and Cole (2004) engage a social model of disability and consider the meanings of vacations to persons with disabilities. Results from Daniels et al. (in press) suggest that severity and complexity of problems encountered, rather than the number, are most salient. They also found pleasure travel constraints for persons with disabilities were unique in that they appeared to be ongoing and interactive rather than hierarchical, as has been suggested in the mainstream constraints literature (Jackson, 2005).

Research that examines the needs of tourists with disabilities is in the early stages of development, with initial findings suggesting a greater complexity of issues than previously recognized (Shaw & Cole, 2004). Although sparse, some of the current literature on the vacation behaviour of persons with physical disabilities also is starting to move beyond access and policy issues by exploring experience in terms of vacation meanings and satisfaction. The constraints, needs, and experiences of individuals with intellectual disability and their families, however, have not been addressed in this literature. Recent critical perspectives on tourism demand research have noted that the ability to engage in vacations and pleasure travel is inequitable and influenced by social and personal identities, including gender, race, (dis)ability, and nationality (Richards, 1999) and, as such, there is a need to extend current understanding by incorporating the perspectives of previously ignored segments of our population.

Research on the impacts of caregiving on pleasure travel, individual, and family leisure has just started to surface. Daily demands of caring for a family member with a disability may contribute to increased stress, depression, health status decline, and caregiver resentment over the loss of leisure (Glad-

well & Bedini, 2004). Findings from Gladwell and Bedini's interpretive study of spousal caregivers and children caring for an adult parent offered two primary themes—changes in patterns and types of leisure travel and issues of entitlement, resentment, and anger. In addition, “impediments to travel” were also described by caregivers as physical, social, and emotional obstacles and hierarchical in nature. These impediments were present regardless of whether the caregiver traveled without the care recipient.

From this review of seemingly disparate areas of existing knowledge (e.g., QOL, tourism research on vacation experience and QOL, family, and persons with disabilities) it is readily apparent that there are major gaps in the literature with respect to understanding the roles and meanings of vacations to families that include a member with intellectual disability. Our aim in this paper is to begin to bridge these gaps by integrating diverse and previously under-represented perspectives into evolving theories of life quality.

Method

The present paper is based on a larger, multi-method, multi-year initiative conducted by a collaborative team of researchers from a variety of disciplinary traditions (e.g., education, family studies, disability studies, leisure, travel and tourism). Consistent with calls in previous literature for greater emphasis on *emic* knowledge in the study of life quality (Verdugo, et al., 2005), a core component in the first phase of this work was designed to generate initial insights about the perspectives of family caregivers on the meaning of quality of life and the factors and experiences that contributed to their understanding. Reflecting this aim, a focus group method of data collection was used, with the resultant data analysed using a grounded theory approach (Strauss & Corbin, 1998).

Focus groups are widely recognized as an effective method for obtaining a breadth of information specific to a concept or issue of interest, and learning about people's experiences and perspectives (Madriz, 2000). Unlike other approaches that are directed by predetermined hypotheses or controlled by existing measures, focus groups enable participants to express themselves, in their own words, in an open and flexible process (Krueger & Casey, 2000). Like all methods, focus groups do, however, have limitations particularly in terms of the depth of information yielded (Cresswell, 1998). Given our purpose in the first phase of the project (i.e., exploring initial insights as a basis for subsequent phases of the research) this method proved appropriate and generated a number of key insights in this underdeveloped area of study.

Participants

Ten families,² represented by 15 family caregivers, participated in the focus groups. Thirteen participants were parents (4 opposite sex couples,

²To reflect the diverse nature of family experiences among individuals with intellectual disability, family is conceptualized in this work as “individuals who think of themselves as part of a family, whether related by blood or marriage or not, and who support and care for each other on a regular basis” (Poston, et al., 2003) and independent of whether they reside in the same household or not.

and 5 mothers), from a total of 8 different families (6 biological and 2 adoptive/foster). Two adult siblings (one a non-primary caregiving male, and one a primary caregiving female) from two families also participated. Most ($n = 7$) of these families had taken part in previous research conducted by the team that examined related indices of life quality (e.g., social integration) using more intensive, in-depth methods of inquiry (e.g., individual interviews, case studies, participatory action research). Given the exploratory aims of the first phase of the present project and our interest in ascertaining a breadth of views that would direct future aspects of the project, this purposive recruitment strategy was selected because it enabled us to build on existing rapport with, and knowledge of, the participants.

The families were predominantly white Canadians with two families including adoptive/foster children from an aboriginal background. Collectively, the families had a total of 34 children, 17 of whom had an intellectual disability. Family size ranged from one to six children in each family ($M = 3.4$), and the children ranged from 2 to 42 years of age ($M = 22$ years). Of the children with intellectual disability, the females ranged from 16 to 42 years of age and the males from 12 to 31 years of age. Typically, the families included three or four children—one of whom had an intellectual disability (70%). Two families, however, had multiple children with a disability and in one foster family all the children had some form of a disability, including intellectual disability.

From a follow-up questionnaire that was sent to the families as part of the member checking process (see data analysis section for further details³), extended demographic information for six families, headed by parental caregivers (i.e., not adult sibling caregivers), provided further insights about their education, employment status, income, and the nature of their children's intellectual disability ($n = 8$). The educational experiences of these parents ranged from being a high school graduate to having a post-graduate degree, with most having at least some university education. In three families both parents worked full-time outside the home, two families had one adult working full-time outside the home and one adult working full-time (unpaid) at home, and one family had one adult working full-time and one adult working part-time outside the home. The household income ranged from \$45,000 to more than \$100,000 (CDN), with the most frequently reported household income in the \$75,000 to \$99,000 per year range. In describing the nature of their children's disability, parents used a number of labels (e.g., Down syndrome, $n = 2$; intellectual disability, $n = 6$) and listed a host of related impairments (e.g., autism, FAS, seizure disorder, cerebral palsy) and health conditions (e.g., diabetes, heart problems, allergies). School aged children ($n = 6$) were in a range of educational placements: from full-time special

³Eight of the families provided feedback on the open and axial coding results, which were sent as part of the member checking process to ensure that the researcher's interpretations were consistent with caregivers' perspectives. The demographic questionnaire that accompanied this summary was completed and returned by 6 families.

education to part-time with one-to-one support in regular education. Additionally, four children received clinical supports and services including occupational, speech, and behavioural therapy.

Focus Groups

Focus groups are “carefully planned discussions” designed to obtain a breadth of “perceptions on a defined area of interest” (Krueger, 1994, p. 6) and, as such, were used in the present study to generate initial insights about key concepts specific to QOL and, the role of leisure (generally, and vacation behaviour specifically). Two members of the research team, both experienced moderators, facilitated three sessions (4 to 6 participants per group) using a question route designed to address the objectives of the research and to ensure consistency across groups while enabling free and flexible expression of ideas.

The question route included opening comments about the topic of study (i.e., QOL), introductory questions to engage the participants in the topic, transition questions related to daily life (nature of a typical day, pace), key questions on factors that contribute to, and detract from QOL (e.g., parents individually, family as a collective, and family member with intellectual disability), and ending questions to summarize the discussion and confirm main points (see Table 1). Two key questions were specific to the purpose in this paper: “What does quality of life mean to you personally?” and “What do vacations away from home contribute, if anything, to your thoughts about quality of life?” A series of probes also were used to enable the participants to elaborate on their views about the meaning of QOL to them personally, and if relevant and appropriate from their perspective, the positive and/or negative influence of vacations. At the conclusion of each session, participants were thanked for their time and contribution and given a \$50 honorarium. Each focus group lasted approximately 90 minutes. Data were tape recorded and transcribed verbatim. Additionally, one of the moderators recorded detailed notes during the focus group to capture any observations that would not be readily apparent from the transcriptions.

Data Analysis

Grounded theory involves the systematic collection and analysis of data for the purpose, ultimately, of generating theory (Strauss & Corbin, 1998). Within this technique the initial level of analysis (open coding) involves identifying concepts central to the phenomenon. As data collection continues, connections between concepts are explored using an axial coding scheme to determine the conditions, contexts, and action/interactional strategies that enable categorization of the data. In the final stage (selective coding) a “story line” is generated that integrates previous levels of analyses and offers conditional propositions or working hypotheses (Strauss & Corbin). This interplay between data collection and analysis—often referred to as a constant

TABLE 1
Examples of Questions and Probes Included in the Focus Group Question Route

Opening comments

- Welcome and explanation of the study purpose, focus group procedures, and confidentiality of information.

Opening/introductory questions

- Self-introduction of the moderators.
- Please tell us a little about yourself.
Sample probes: Have you taken part in a focus group before? How many children are in your family/household?

Transition questions

- Thinking about your typical day, is there one word that best describes your pace of life? What would it be?
- When you think of a typical day in your household generally, is there one word that best describes the pace of your family life?

Key questions

- QOL is one of those ideas you hear a lot about these days, but nobody has a really good idea about what this means to different individuals and families. Thinking about QOL from your personal perspective, how would you define what this means to you?
Sample probes: What would you say contributes to QOL for you personally? What detracts from your QOL?
- When you think of the things you do for enjoyment—like leisure (recreation)—does this have any effect on what you see as a life of quality? If so, can you tell us more about this (positive and/or negative)?
Sample probes: What about vacations away from home, do these in anyway influence your views about QOL (e.g., positive and/or negative)?

Ending/summary questions

- Based on everything we've talked about, how would you describe your definition (vision) of QOL? What's the biggest detractor? What's most important?
- Before finishing up, is there anything else you want to say about what we've been talking about tonight? Did we miss anything?

comparative method—is a central feature of grounded theory (Glaser & Strauss, 1967).

In the present paper, results from open coding (i.e., process for identifying key concepts central to the phenomenon) and axial coding (i.e., developing categories that synthesize key concepts) of data from year one of the project are the main focus. These findings are the basis for subsequent phases of data collection and selective coding (i.e., integrating previous levels of analyses in offering conditional propositions or working hypotheses; Strauss & Corbin, 1998).

A series of intensive, individual and team approaches to data analysis were conducted using NUD*IST (QSR N6), a computer based qualitative data management system, to facilitate the process. The first phase was conducted individually with each member of the team reflectively reading and

re-reading the focus group transcripts and documenting key concepts (i.e., open coding). A 3-day data analysis workshop was then instituted. During the first day, each team member presented the results of his/her individual analysis, with the remaining two days devoted to a collective, iterative process of examining and re-examining each of the proposed key concepts in relation to one another and the data (which was the ultimate criterion for determining whether a concept had “earned” its way into the analysis), and finally, identifying possible categories appropriate for synthesizing the central ideas. Following the workshop, one team member developed narrative summaries and conceptual maps (developed using Decision Explorer; Banxia Software, UK) of the collectively determined results. All team members subsequently reviewed and provided critical feedback and further revisions were made. Once this iterative approach to analyst triangulation was completed, a summary of the initial open and axial coding results was sent to the participants (i.e., member checking) as a further strategy for assessing the trustworthiness and credibility of the findings. Of the 80% who returned their evaluations, there was unanimous agreement that the result summaries were consistent with the breadth of views expressed during the focus groups and captured their individual perspectives as well.

Results

Categories, sub-categories, and defining concepts are utilized as the organizing framework for presenting the results. These findings highlight family caregivers’ perspectives on (a) the meaning attributed to their personal understanding of QOL and, (b) the role of vacation travel. A brief overview of interpretations pertaining to leisure generally also are included as additional context for understanding leisure in these families’ experiences. Figures 1 and 2 summarize the results, with stretched octagons depicting categories, defining sub-categories enclosed within ovals, and rounded rectangles linking key concepts with respective categories or sub-categories. In the following text, categories are bolded, sub-categories underlined, and concepts italicized.

Quality of Life

Health, happiness, and enriching connections reflects the central meaning caregivers attributed to QOL as it applied to them personally. “Having one’s health” and basic life needs satisfied are foundational: “I think you start with basic needs—like health, having good health is sort of number one, and there’s things like being sheltered, clothed, and fed . . . it’s hard to have a quality life if those basics aren’t met.” Adding to this view of basic needs, several caregivers expressed a sense of *good fortune* and the importance of having the financial means to afford enriching opportunities:

Finances definitely are important in getting past the basics. I mean, I often sit back and think if we didn’t have the jobs that we have, and the money that we

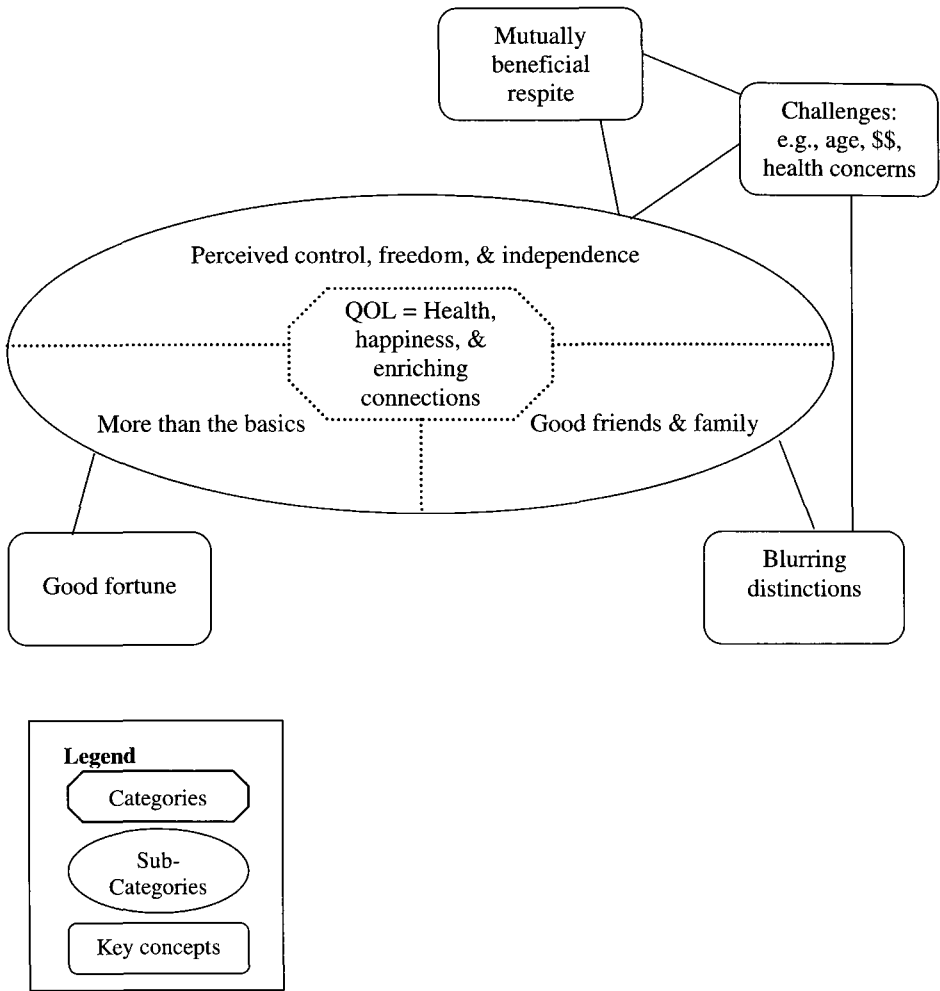
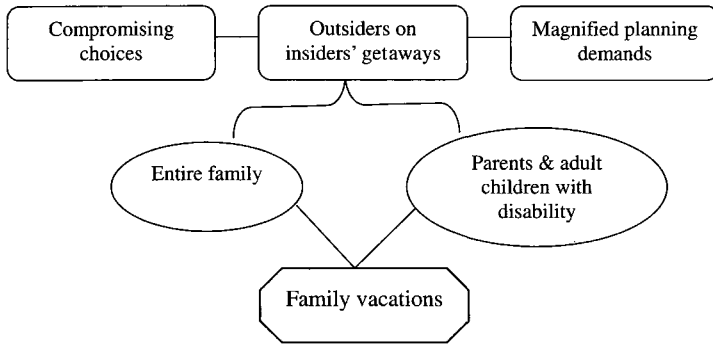


Figure 1. Summary of key findings pertaining to the meaning of QOL as defined by family caregivers and influencing factors (i.e., non leisure or vacation related).

have, all the things that we get to do right now for our family and Simon⁴—if he was born under different circumstances, things could look very different for him . . . I’m not saying you have to be rich, but you have to have enough . . . because finances play a really big role in your quality of life.

While recognizing the importance of satisfying basic needs, caregivers also were emphatic that *more than the basics* were essential to living a life of quality. Meaningful interactions and social connections with *good friends and family*, in particular, were deemed critical:

⁴This is a pseudonym as are all other names used in the quotes.



Vacations

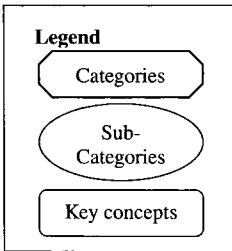
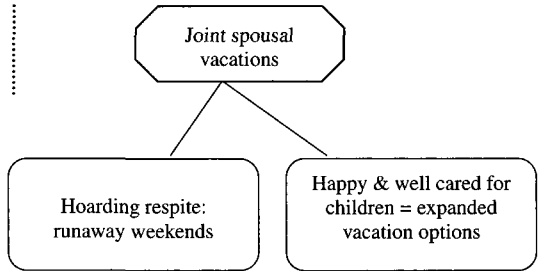
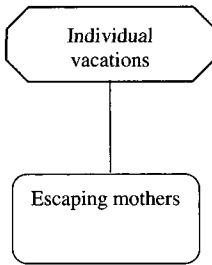


Figure 2. Summary of key findings specific to vacation patterns and issues.

With health and basic needs covered, that's the first hurdle but living a good life is about so much more. It really comes down to good friends, family to interact with. This is what gives you a feeling of contentment. That's what my quality of life is, when I feel contented, I feel happy. I can't think of anything else that matters or I really want.

While sharing the value and central role of friends in defining life quality, initiating and sustaining these connections was not always easy:

I think friendships are really important too but because we have an unusual kind of family, they aren't always easy to come by . . . not a lot of people want to involve themselves with you if you have different kinds of kids or a lot of kids. It's like whoa! So, you know, the friends who are good friends to us are very important, and our family too.

Perhaps this concern accounts for some caregivers placing family relationships at the top of the social network hierarchy:

Social networks, your friends are for sure important . . . but being in tune with immediate family, siblings is most important. Our world and especially our kids with a disabilities' world, really is about that because other social outlets are limited. So family is really most important.

This comment also alludes to the difficulty many caregivers, especially parents, had in distinguishing their personal views about life quality from those of their children—particularly those with intellectual disability (i.e., *blurring distinctions*):

Well, I mean, you want the same basic things for yourself, your children and your family. You want them to have health, happiness, you want them to be contented, successful in whatever endeavour they take on . . . for my “normal” children I was able to let go of some of these expectations when they became adults, but for our handicapped child it’s a different issue. You see the cycles he goes through, you worry about if he’s in danger of losing his job or if he’s not taking care of his health the way he should . . . that’s a big detraction and gets all mixed into quality of life . . . mine, his, ours.

Establishing and maintaining a degree of personal control over life choices, freedom to engage in valued activities/interactions, and independence also were central concepts in caregivers’ views about the meaning of QOL (i.e., *perceived control, freedom, and independence*).

Well I’m thinking a little bit along the lines of a certain measure of control or choice in your life. Myself, I like to have stimulating things to do . . . that’s what gets me through all of the cooking, cleaning, the washing and everything—that after all these years I’m tired of doing actually! . . . that to me is a good life at my stage.

Often introduced, as a critical issue in the context of these discussions, was the importance of respite from caregiving responsibilities:

Respite is huge in quality of life for us and our children. He gets to be involved with other people who take him out to a movie or bowling or whatever and that is how I get some kind of regeneration and control over my own life.

While widely regarded as essential, *mutually beneficial respite* was frequently inaccessible, insufficient or of poor quality:

I love my respite! Without the break, I just don’t know what I’d do . . . It hasn’t always been a good experience, you know, lots of time you can’t get it when you need it, and it means lots of people in and out of your life. So even if you can get it, it isn’t always good. Denise’s daughter (i.e., respite worker) is a saviour for us and a real boost to my quality of life.

Beyond available respite, achieving desired levels of control, freedom, and independence presented challenges for caregivers depending on family life stages (i.e., families with younger children), parental employment demands (e.g., “travelling fathers”), financial resources, and the health or support needs of the child(ren) with a disability (i.e., *challenges*). Linking several

of these factors together, the mother of a son who had recently moved into a supported living situation offered:

Choice, I like the word choice because it means you can decide to do things or not depending on how hectic things are . . . also, having enough money so you're not just fighting to exist, enough money so you can do some interesting things, like trips or having some choice of places you'd like to go or things you'd like to do. After all these years of looking after Stephen, now that he's on his own, I finally feel like I'm at a stage in life where I have more choice, and a certain freedom to just let go and do more of what I'd like.

Another mother, with two small children of her own and an adult sibling with intellectual disability went on to explain:

You guys are parents; I'm not a parent of my sister. I'm sandwiched with two little ones of my own, a husband who is always on the road, and my sister to care for. Someone always needs a piece of your time, everyone always wants a chunk of you. So that doesn't leave much left over or much control over what you do . . . you just deal with demands as best you can.

Personal control and independence of caregivers also were affected when family members had additional impairments (e.g., seizure disorder) or health (e.g., diabetes) concerns:

Michael seizures a lot, so he really can't be left alone. Someone has to be with him 24/7. You don't have control over when something might happen and to make sure he's safe you can't be running off doing your own thing.

Anthony's Down syndrome is not an issue at all, diabetes, now that took some adjustment that really tied us to home at first and still is a concern that we have to take into account.

Leisure and Leisure Vacations

Typically, "leisure, what leisure?" was the implied response to questions about regularly engaged in, and personally meaningful individual leisure pursuits. Juggling work and family obligations, and securing childcare sufficient for meeting general, disability and health specific needs were typical explanations for limited involvements.

Part of it's being working parents but on top of that there is (sic) constant arrangements to be made for childcare and other things that demands so much time and effort, you have to be thinking all the time. At the end of the day, you're just too tired . . . no energy to do anything even something I enjoy doing just for fun, is a luxury I don't have very often.

Less frequent, novel leisure expressions were more the norm. Specifically, three distinct categories of vacations were evident: *individual* (one caregiver), *joint* (spouses only), and *family* (both spouses and one or more of the children).

Escaping mothers captures the central concept of the individual, one parent vacation pattern (i.e., *individual vacations*) in which mothers sought "self-indulgent getaways" that were described as "not ideal" but essential for re-

juvenation and a temporary “break from caregiving responsibilities.” One of the appeals of lone parent vacations appears to be the reduced planning demands, particularly pertaining to childcare:

You don't have your husband with you so you don't have all that preparation and everything you have to do when you leave your child with somebody else—you're worn out by the time you leave, right . . . not ideal, but getting away by myself is also a much needed opportunity.

Additionally, reclaiming personal time and space was a strong motive for some mothers to vacation alone:

I escaped on a vacation to Winnipeg, to the Hotel Fort Garry once . . . I must have had 6 baths a day and nobody knocked on the door—actually I didn't even close the door! My time and my space was all mine.

Joint vacations involving both parents were limited (“We've had one week away from our children in 24 years.”), the reasons for which are addressed by two related but distinct concepts (a) *hoarding respite for runaway weekends* and (b) *happy and well cared for children expands parental vacation options*. Specific to families with children with disabilities living at home, hoarding respite time was a direct function of limited access to formal respite, typically in the form of a paid support person provided by an external community agency:

We get such limited paid respite support that we've actually saved our respite for the last few years so we could take it in one lump sum . . . that way my husband and I can go away together—that is our runaway week—we don't take the children, we have to do that for our own mental sanity once in a while.

For caregivers of children with disabilities who live outside the family home, relaxing vacation options were contingent on the knowledge that their children were happy and well cared for.

Now that Jeannie is in a group home where she's happy and has good support from the workers there, Tom and I can go places on vacation without worrying about who is looking after her, and if they are doing a good job. It's really built our quality of life together now that we have this sharing time, which we never had before.

Family vacations assumed one of two sub-patterns: those including the *entire family*, and those including *both parents and their adult sons/daughters with a disability*. Vacations involving all family members typically reflected the family's life stage: “Our kids are younger, so we are pretty much in the family holiday mode. We load up the kids and the car and do it all together most of the time.” For other families with adult children with a disability living at home, vacations were a means of accessing travel benefits such as: “getting away from routine”, “doing and learning new things,” “rewarding” efforts in other life domains (e.g., work), and simply for the “enjoyment of having done it.”

While viewed as an important facilitator of family and individual life quality, family vacations often introduced issues that left most caregivers won-

dering, at one point or another, whether “it’s easier just to stay home.” These issues revolve around three central ideas: *compromising choices*, *outsiders on insiders’ getaways*, and *magnified planning demands*. The first concept, *compromising choices*, involves the strong influence of disability and health related needs on destination choice:

We just came back from Disney World. We took Jason for 4 days in January. All the cartoon characters and rides were right up his alley even though he’s an adult. It was great for him but it was a nightmare for us. We’re in our 60’s you know.

Our son is on tube feeding and oxygen, which really limits where we can go. Calculating oxygen tanks, how many to take and worrying about carrying that stuff in the van . . . that makes going to Brandon (250 km), like we did last year for a few days, our limit.

Outsiders on insiders’ getaways addressed the tension between the need to include aides/respice workers on family vacations and the implications—financially and in terms of experience quality (i.e., including non-family members on family vacations).

We have twice taken our outside worker because you need to have some part of the day when you’re not—you need good child care basically, someone who knows how to handle your child’s needs. But that comes at a big cost cause airfare comes out of our pockets and so does the hotel; and then you have that outside person on your private family time . . . but I don’t know whether we could go on vacation any other way.

Finally, accommodating unique childcare and, in some case, health needs of family members with intellectual disability *magnified planning demands*, which limited spontaneity and frequency of family vacations.

We have friends that can pile all their kids into the van at 4:00 o’clock on Friday afternoon and say we’re going to Grand Forks for the weekend, and off they go. We have to make a critical path, spend days on end getting all the arrangements made, finding out whether the place we’re going to stay has everything we need, and getting every detail organized. Then we have to spend at least two days getting Nathan ready. We have to explain and prepare him for every step of the way . . . what time we are going to get in the car, when we’re going to get there, where we’re going to eat supper. Anything that mixes up his routine can be a major problem, so we have to do this or just stay home.

Discussion

The hectic and escalating pace of daily life is a well-chronicled worldwide social phenomenon (Shields, 2003) that has stimulated both academic and popular media discussions about life quality. Within academic literature in the area of intellectual disability, the focus on QOL stems from its position as the overarching goal in service development, delivery and evaluation. The meaning of QOL and how individuals and families achieve it remains unclear, however. For the participants in this study, personal health and basic need fulfilment were foundational elements, with QOL being a much

broader and encompassing concept that integrates meaningful and enriching social connections with friends and family, and perceived control, freedom and independence. Financial resources, quality respite, and health and impairment concerns specific to the family member with a disability also were key factors that had the capacity to facilitate or constrain life quality. Respite and health/impairment issues also illustrate how caregivers' personal perspectives about QOL often morph with concerns affecting other family members—hence blurring the distinction between individual and family conceptions of life quality.

Vacations taken for individual escape, joint (spousal) relaxation, or for family fun, interaction, and learning link these forms of leisure expression to QOL. In particular, family vacations contributed to the value added elements of life quality—healthy, happy, and socially enriching experiences. When vacations provided opportunities for personal control, freedom, and independence of individual or multiple family members they are key contributors to QOL, otherwise they are detractors. Revealed as unique to this research and population group, are the complex features of family vacations that involve a child with an intellectual disability. For example, the inclusion of “outsiders” in a family ritual, the need to bank respite time, and the chance to relax, or see and do new things, illustrates how typical and atypical costs and benefits of vacationing are magnified.

Connections to Existing Quality of Life Literature

Findings from the present study are consistent with contemporary literature in which QOL is defined as a broad-based, multidimensional concept that transcends several distinct constructs (e.g., life satisfaction, well-being) and is composed of a number of core elements or dimensions (Cummins, 2005; Rapley, 2003; Schalock, et al., 2002). Health, basic needs (e.g., food, shelter, clothing), financial security, happiness, and leisure—identified in the caregivers' self-definitions—have all been identified in previous research and are included in both individual and family conceptual models of life quality (Brown, et al., 2003; Poston, et al., 2003; Schalock, 2000; Schalock, et al., Turnbull et al., 2004). Difficulties maintaining friendships because of the discomfort some associate with families that include a member with disability, concerns about adequate respite, and excessive planning demands that undermine spontaneity in family life are examples of other key findings from the present study that complement emerging knowledge in this area (Brown, et al.; Poston, et al.).

Existing literature, however, provides limited insight about the relative importance of the defining elements of life quality and their relationships to one another (Cummins, 2005). For example, in Schalock's (2000) model, health is a central facet of physical well-being, with basic needs falling within the material well-being domain. Caregivers in our study clearly linked health (mental and physical) with basic needs and placed “having one's health” as the single most important foundation to building life quality. Additionally,

previous literature positions happiness as a transient affective state (Deiner, 2000), while our data suggest that caregivers view happiness and a sense of contentment in life as ultimate indicators of life quality. Using the term contentment in this context, caregivers implied acceptance of life circumstances rather than an evaluation in relation to any particular standard, which well-being as a global assessment of satisfaction with one's life suggests (Deiner).

Our interpretation of the caregivers' perspectives on the meaning of QOL also suggests what appears to be a hierarchical conceptualization of this notion in which fulfilling basic needs is fundamental, while enriching social relationships and personal control, freedom, and independence are higher order influences that elevate life quality to another level. Although identifiable as distinct factors, they seem to be tightly interconnected and operate in a complex and reciprocal manner. Albeit the product of early stages of research, the reported findings shed initial light on potential variations in the relative importance of some of the previously identified core elements of QOL and possible interconnections that require further consideration.

From a theoretical perspective, the results of the present study also support the use of frameworks that accommodate dynamic influences and interactions that shape both individual and family perspectives about life quality (Cummins, 2005; White & Klein, 2002). Systems theory, which is the basis of Turnbull and colleagues' (2004) conceptual model of family life quality, has been advanced as one option in-keeping with this perspective. Poston et al.'s (2003) extension of this model proposed six individual orientation domains (advocacy, health, productivity, emotional well-being, physical environment, and social well-being) as core components of individual QOL, which when fused with the four domains of family orientation (i.e., daily family life, family interaction, financial well-being, and parenting) become the "context for interaction and reverberation" (p. 321) that produces family conceptions of life quality. While consistent with the principles of systems theory, and intuitively logical, the dynamics of this process remain unclear and raise questions about whether factors that can be delineated conceptually are as neatly segmented in the realities of people's lives. In our study, the difficulties caregivers had in separating concerns specific to the family member with intellectual disability (e.g., maintaining health, self-care and their role as primary facilitators of vacation opportunities) from their personal and family conceptions of QOL, in particular, underscore this point.

Consistent with this concern, Gallimore et al. (1989) argued that the application of systems theory is challenging because "if everything is plausibly connected to everything else, how should the different levels or units of analysis be organized?" (p. 217). Ecocultural niche theory, or simply econiche theory, has been offered as an alternative approach (Gallimore et al., 1989). Unlike systems theory in which stress is posited as the activator of family adaptation, ecocultural niche theorists presume family accommodation to be the functional response to both serious and mundane hassles of daily life, which may or may not be perceived as stressful (Gallimore, et al.,

1993). The essence of this approach is to examine daily family routines and the congruence of these activities with individual needs of all family members, and the influence of these routines in fostering child development and learning (Gallimore et al., 1996).

Although identified as an important expression of leisure in family life (Jo et al., 2004), the notion of family vacations as an ecocultural niche has not been considered or examined previously—probably because of their positioning as distinct departures from daily routines (Richards, 1999). The kinship enhancing and educational motives frequently cited in relation to pleasure travel, however, appear to be highly consistent with coherent family adaptation, and an extension of development-sensitive opportunities (e.g., for promoting child growth and learning) in regular activities. Recently published guiding tenets in contemporary QOL research add impetus to this notion of looking beyond frequency or infrequency of engagements by advocating a greater emphasis on personally and collectively *valued* experiences and contexts (Schalock et al., 2005; Verdugo et al., 2005).

The value caregivers in the present study attributed to vacations and the qualities they attributed to these experiences, resonate with the foundation of econiche theory—adapting to hassles “in life” and the priority afforded to contexts for development-sensitive opportunities—and extend it beyond the scope of daily activities. For example, individual and joint vacations were opportunities for respite from caregiving responsibilities and rejuvenation, which could be assumed to enhance one’s ability to subsequently manage all manner of challenges that come with daily life. The expressed motives of caregivers for taking vacations with their adult family member with intellectual disability—“getting away from routine,” “learning new things,” and “simply for the enjoyment of having done it”—all resonate with development-sensitive aims in more routine forms of daily activities. Given these qualities and the intensive nature of this unique form of family leisure, it seems appropriate to conceptualize vacation behaviour within an ecocultural niche framework as a means of further exploring the influence and role of less frequent, but nonetheless important, family rituals in life quality.

Connections to Existing Travel Literature

The results show that motives for taking vacations vary by pattern/type of holiday (joint, family, individual), and are consistent with dominant social psychological theories of tourist motivation (Crompton, 1979; Dann, 1977; Harrill & Potts, 2002; Iso-Ahola, 1982; 1983). In fact, escaping routine personal and interpersonal environments and/or seeking personal and interpersonal rewards (Iso-Ahola, 1982; 1983) through vacations were expressed by participants as illustrated above. When considering the findings in light of destination choice and family vacations, the influence of novelty and education motives (i.e., Crompton’s 1979 cultural motives) in destination selection may be altered or more closely linked to disability/health concerns. In other words, independent of the “pull” of cultural motives and destination

offerings, destination choice in family vacations including the individual with intellectual disability appear to be driven by needs, interests, and concerns specific to health and disability factors. Furthermore, our findings speak to the issue of vacation decision-making and the influence of children in this process. In previously reported research (Madrigal, 1993; Seaton & Tagg, 1995), age is generally denoted as the strongest influence—with young children having the greatest impact of vacation decision-making. From the present study it is evident that adult children with intellectual disability have a similar effect as they continue to play a major role in destination decisions and activity choices. Age, therefore, is neither the only child-related nor perhaps the most important influence in families that include children with disabilities.

The inclusion of aides or *outsiders on insiders' vacations* distinguishes this population group and implies a willingness to make social and economic compromises or sacrifices in order to have a vacation away from home. Notions about vacations as income inelastic (Ryan, 2003) and as valued contributors to life quality are re-enforced by such behaviour. Findings from the present work also add to the sparse literature on caregivers and the role of leisure and vacations. Results seem to highlight the importance of distinguishing between caregiving for a spouse or parent and caregiving for children even when they are adults. This observation may help explain why resentment, for example, was neither noted by caregivers in the present study nor evident in any other concept/category of our findings, yet it was reported as a factor in Gladwell and Bedini's (2004) study of leisure and vacations among spousal caregivers. Caring for one's child is a socially entrenched expectation, even when that role is extended well beyond the time most parents have "launched" their children, and hence "resentment" as a theme among caregivers in the present context was not evident.

Lastly, this work begins to address the critical perspectives on tourism demand that note the inequitable nature of pleasure travel that has omitted the voices of many outside of traditional tourist market segments based on their social and personal identities, in this case, families that include a child with intellectual disability. One extension from our work is the suggestion that "collective identity" also may play a role.

Conclusions and Future Directions

The present study is a small scale exploratory foray into an emerging area of inquiry that transcends several fields of study—leisure, vacation behaviour, and QOL from a disability studies perspective (specifically, intellectual disability). Inherent in efforts of this nature, there are limitations to this research (i.e., focus group method, large gaps in existing knowledge; limited socio-economic and cultural diversity of participant group) that can only be resolved through intensive, long term study. As previously stated, the focus group method was selected as it was consistent with the purpose of this phase of the reported research—to collect a *breadth* of family caregiver perspectives

that would provide the foundation for subsequent study. Future research that employs qualitative methods that generate more in-depth data (e.g., interviews, case studies) is essential for extending and substantiating the present findings. Recruiting participants from non-dominant cultural groups also is an issue that must be addressed in future studies. In the present work, the participants were mainly from white, middle-class backgrounds, which we raised as a point of criticism in existing literature and highlighted as a concern that has limited understanding of the needs and interests of families that include a member with intellectual disability. While our participants were exclusively drawn from the latter group, which addresses one part of this criticism, the degree of cultural and ethnic diversity was a limitation. Throughout the year in which the study took place, the research team actively attempted to address this concern. Specifically, since the city in which the study was based is home to one of the largest urban Aboriginal (First Nations and Métis) communities in Canada, we focused our recruitment efforts in this area. We hired a person from the Aboriginal community to direct the process and while many excellent connections were established that may be useful in the future, we were unable to incorporate Aboriginal participants into this phase of the research. Establishing credibility and trust relationships is imperative when conducting research with “vulnerable populations” generally, and based on the feedback from the agencies and individuals we contacted in the Aboriginal community, this is a particularly important and a time consuming undertaking especially when the topic of interest might be interpreted as evaluative (i.e., in this case an “evaluation” of family functioning and/or parenting skills).

Despite these limitations, the results and discussion highlighted in this paper offer an important and unique extension to our limited knowledge base about life quality and the influence of vacations from individual and family experiences beyond those of dominant population groups. From our research to this point, it is clear that many factors influence the meaning family caregivers of individuals with intellectual disability attribute to QOL and much remains to be learned about the interactions and experiences that influence these constructions. It also is evident that leisure and more tangibly, vacations play a key yet not always readily achieved role.

Focusing on the challenges identified in enacting leisure and vacations alone offers a number of questions requiring closer scrutiny if policies and services that support families that include a member with intellectual disability are to be enhanced. For example, how might policies governing respite be modified to facilitate greater access and flexibility according to family priorities and needs? What role might service agencies play in reducing level of care requirements that would enable valued and meaningful family interactions—including enjoying vacations with the entire family? According to the results of our study, providing blocks of quality respite time, without retrenching regular respite is critical for enabling caregivers to relax, and to fully enjoy their vacation experience knowing that their family member with a disability was engaged in quality respite that involved fun, engaging and safe activities. Respite of this nature would not only promote the rejuvenating

benefits of leisure and vacations but also enhance perceptions of control, freedom and independence—core elements of life quality to the caregivers in this study.

For the tourism industry that delivers vacation experiences (e.g., transportation, accommodation, and events/attractions) how might information accuracy and planning assistance both pre-trip and at the destination be enhanced to address the unique interests of families that included children with a disability? Providing day care for travellers with children has become standard fare in many accommodation locales (e.g., resorts, hotels, cruise ships). For families that vacation with adult care recipients with intellectual disability, these services may not be accessible given the age of their family member or appropriate, especially if they have added health related needs. Perhaps expanded inclusion policies or offering adult care programs with trained staff could accommodate these very practical concerns. In an aging society with increased focus on family caregiving, such a service may well have broad-based customer appeal.

In conclusion, it is incumbent upon researchers and professionals alike to advance knowledge and practice in ways that reflect the diversity of families and individuals in contemporary society and address their unique backgrounds, characteristics, and life contexts. Soliciting and listening to the “voices” of family caregivers of individuals with intellectual disability is an important extension to our traditional reliance on academic and/or professional assumptions about the meaning of life quality, and the dearth of knowledge about leisure and vacations in facilitating or constraining QOL. As products of an initial exploration in this area, the findings from the present study will guide subsequent phases of this research and may stimulate future inquiries that enhance knowledge and practical insights for better serving families that include members with intellectual disability.

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