PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITY: PERSPECTIVES ON LEISURE, VACATION PATTERNS, AND LIFE QUALITY

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Introduction

Quality of life (QOL) is difficult to define, conceptually, and a challenge to measure methodologically (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). Leisure, generally, and vacations, specifically are often identified as positive contributors to, and essential elements of life quality (Gilbert & Abdullah, 2004; Heyne et al., 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, martial stability, and satisfaction with family life are common areas of interest (Horna, 1989; Hendry, et al., 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 et al., 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 and their families (Mactavish & Schleien 2004; Shaw & Dawson, 1998).

Results from an emerging area of leisure research that focuses 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). 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 useful microcosm for further study. This notion was the impetus for one aspect of a three year, multi-phase initiative that addresses a broad range of questions including the symbolic and instrumental relationship between leisure (generally and vacations specifically) and life quality, and the interaction/influence of individual, family, and external factors in informing this relationship. Drawing on results from the recently completed first year of this project, this presentation will include parents' perspectives on the meaning of QOL and the role various patterns of leisure, as exemplified by vacation behaviour, play in its construction.
Method

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 encompasses individual and family perspectives, and identifies possible links with extant knowledge about QOL and related areas (family adaptation, leisure). This purpose is readily accommodated by grounded theory, which involves the systematic collection and analysis of data for the purpose of generating theory (Strauss & Corbin, 1998). Results of 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 will be the main focus in our presentation. These findings are the basis for subsequent phases of data collection and selective coding (i.e., integrates 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 and triangulation produced the results that will be presented. NUD*IST (QSR N6), a computer based qualitative data management system, was used to facilitate the analysis and conceptual maps were developed using Decision Explorer (Banxia Software, UK). Focus groups, the principal means of data collection, were intended to generate initial insights about key concepts specific to QOL and, the role of leisure. Two members of the research team, both experienced moderators, facilitated three sessions (n = 4 to 6 participants per group) using a questioning route designed to address the objectives of the research. The questioning route ensured consistency across groups while still enabling free and flexible expression of ideas. Fifteen individuals—13 parents (4 opposite sex couples, and 5 mothers) of children with intellectual disability (n = 16, ranging from 12 to 45 years of age) and two adult siblings (one non-primary care giving male and one primary care giving female)—who had participated in previous studies conducted by the research team were recruited for the focus groups. This purposive recruitment strategy was adopted as a means of linking previous studies by the research team on related indices of life quality (e.g., social integration) and establishing a longitudinal aspect to the present research.

Results

Results are organized by the categories and key concepts parents’ associated with: (a) the meaning attributed to their personal understandings of QOL and, (b) the role of leisure and vacation travel. Categories are denoted by underlined text and key concepts are italicized.

In identifying concrete factors that contributed to parents’ personal notions about the meaning of QOL, meeting more than basic needs was a foundational concept: “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.” Happiness and enriching connections were identified as important value added elements; while maintaining some degree of personal control over life choices, freedom to engage in valued activities/interactions, and independence were essential contributors to QOL.

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.

Achieving desired levels of personal control, freedom, and independence was more or less challenging for most parents 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. Independent of these factors and variable degrees of satisfaction, the importance of control, freedom, and independence in life quality was invariably embedded in parents’ views about leisure and vacations in particular.

Typically, leisure, what leisure? was the implied response of parents to questions about regularly engaged in, and personally meaningful individual leisure pursuits. Juggling work and family obligations, and securing childcare sufficient for meeting general and disability specific needs were typical explanations for limited involvements. Less frequent, novel leisure expressions were more the norm. Specifically, three distinct sub-categories of vacation behaviour were evident: individual (one parent), joint (parents only), and family (both parents and one or more of the children).

Escaping mothers captures the central concept of the individual, one parent vacation pattern in which mothers sought “self-indulgent getaways” that were described as “not ideal” but essential for rejuvenation and a temporary “break from care giving responsibilities.” Joint vacations involving both parents were limited (“…we’ve had one week away from our children in 24 years.”), the reasons for which are inferred by two related but distinct concepts: (1) Hoarding respite for runaway weekends (i.e., specific to families with children with disabilities who live at home. Limited access to formal respite, typically a paid support person provided by an external community agency, which leads families to “save this time to use in one lump sum”); and (2) Happy and well cared for children expands parental vacation options (for parents of children with disabilities who live outside the family home, relaxing vacations are contingent on “not worrying about who is looking after Jeannie, and if they are doing a good job.”). Family vacations assumed one of two sub-patterns: those including the entire family (typical in households with children under age 21) and those including both parents and their adult sons/daughters with a disability. For some families, this was a function of having children living at home and for others it was a way of ensuring that adult children with a disability could access travel and its benefits—“getting away from routine”, “doing and learn new things,” “rewarding” efforts in other life domains (e.g., work), and simply 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 parents wondering, at one point or another, whether “it’s easier just to stay home.” These issues revolve around three central ideas: compromising choices (i.e., destination choice strongly influenced by the child with a disability); outsiders on insiders’ getaways (i.e., the expense/presence of aides/respite workers on the family vacation); and magnified planning demands (i.e., limited spontaneity and intensive advance planning required to address, for example, childcare needs, health concerns).
Discussion

The hectic and escalating pace of daily life is a well-chronicled worldwide social phenomenon (Shields, 2003) that has stimulated broad based academic and popular media discussions about quality of life. The meaning of QOL and how individuals and families achieve it remains unclear, however. For the participants in this study, QOL was about more than basic needs and vacations for individual escape, joint (parental) relaxation, or for family fun and learning were clear examples of leisure patterns that contributed to this value added—healthy, happy, and socially enriching—view of life quality. The results also 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). When vacations provide 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, illustrate how typical and atypical costs and benefits of vacationing are magnified.

Practical Implications

As the first phase of a multi-phased project, the issues identified here will be explored further in subsequent components of the research. At this point, it is clear that for parents of a child with intellectual disability, their perspectives on the meaning of QOL are connected to leisure and more tangibly, to vacations. In particular, the findings offer an important and unique extension to our limited knowledge base on quality of life, vacations, and persons with disabilities by recognizing and understanding individual and family life contexts and experiences beyond those of dominant population groups. Results have practical implications for the myriad of systems and services that strive to provide support for families with a child with intellectual disability, for example the need to provide blocks of respite time, without retrenching regular respite. For the tourism industry that delivers vacation experiences (e.g., transportation, accommodation, events/attractions) information accuracy and planning assistance both pre-trip and at the destination are absolutely critical to facilitating quality vacation experiences and hence QOL for all family members.

References


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