

Quality of Life for Children with Developmental Disabilities:

A New Conceptual Framework

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Abstract

Although there are frequent references to quality of life for children with developmental disabilities made in the context of government policy, service programs, and interventions by professionals, the construct has not been well defined and conceptualized in the literature. Accordingly, the research reported here describes the qualitative methods used to develop a conceptual framework of quality of life for this group of children. The major elements of the emergent conceptual framework and its significance are also outlined.

Optimizing quality of life is often held out as a broad goal of policies, services, programs, and individual interventions for children with developmental disabilities and delays (Zekovic & Renwick, 2003). In recent years much attention has been given to defining and conceptualizing this complex construct and operationalizing it in the form of measurement tools for adults with developmental disabilities (Renwick, Brown & Nagler, 1996; Schalock, 1996). However, there has been little attention to doing so for children. In essence, what it actually means to improve quality of life for this group of children has not been well delineated. Thus, conceptual frameworks of quality of life are needed to flush out what the concept means and to provide a foundation for development of useful instrumentation to tap this construct with respect to this group of children.

To date, few attempts at conceptualizing quality of life for children that include those with developmental disabilities have been made. Collectively, these have tended to focus on three main issues. Specifically, some emphasize measurement rather than the complexities of the meaning of the concept (e.g., Varni, Seid & Rode, 1999). Others are concerned with health

and disabilities rather than the child's life as whole (e.g., Ravens-Sieberer & Bullinger, 1998; Varni et al., 1999) or have been based in part on specific normative considerations particular to a geographic area (e.g., Lindstrom, 1994, draws on Nordic normative data).

Accordingly, the purpose of the research reported here was to develop a conceptual framework of quality of life for children with developmental disabilities as part of a multi-phase program of research carried out at the Quality of Life Research Unit (University of Toronto). The assumptions underlying this first phase of the research were that quality of life is a multidimensional, holistic construct which can be viewed as both a dynamic process that can change over time and an outcome that can be assessed at any point(s) in time (Renwick & Brown, 1996). Further, children with developmental disabilities grow and develop as individuals over time. The objectives of the next phases of the program are to develop and validate a package of instruments based on the conceptual framework described here.

Method

The cross-sectional study design included parents of children in three age sub-groups (3-5, 6-8, and 9-12 years). The sample of parents was heterogeneous in terms of characteristics that could affect their perceptions of their children's quality of life (e.g., socio-economic status, cultural heritage, age, rural or urban geography, child's diagnosis). This approach to sample selection was intended to enhance transferability of results and, ultimately, contribute to the overall applicability and usefulness of the framework and the instrument to be based on it. Participants were recruited through community-based organizations providing service to children with developmental disabilities and their families. All participants provided written, informed consent. All methods and procedures received prior ethical approval from the University of Toronto.

Participants were 30 parents of children with developmental disabilities from urban and rural areas in south-central Ontario. They included birth, foster, and adoptive parents as well as kinship care providers of children who have developmental disabilities and delays. A service practice definition of developmental disabilities was used for the purposes of this study (see Brown, 1999 for details).

Participants were interviewed in their homes by trained interviewers who followed a semi-structured interview format. The audio-taped interviews lasted 60 to 90 minutes and consisted of open-ended questions and probes

focussed on parents' perspectives about what made life good and not so good for their children. In addition to this qualitative data, socio-demographic and disability-related information was also obtained from the participants. Interviews were carried out until saturation of the major emergent themes was achieved.

Feedback on the conceptual framework that emerged from the qualitative data analysis was obtained through member-checking activities with a subsample of 8 participants involved in the face-to-face interviews, and an additional group of 7 parents of children with developmental disabilities who did not take part in the in-home interviews. The purpose of this feedback was to: (a) verify the authenticity, relevance, and applicability of the framework; (b) identify missing issues; and (c) evaluate the terminology employed in labelling and describing the components of the model.

Results

Descriptive results

Descriptive statistical analyses were performed for the socio-demographic and disability-related data. Eight parents had children aged 3 to 5 years, 10 had children aged 6 to 8 years, and 12 had children between 9 and 12 years. As is common within this population of children, boys ($n=23$) were over-represented as compared to girls. Twenty birth parents, 6 foster parents, one adoptive parent, and 3 other kinship carers participated. They came from diverse ethnic and racial backgrounds (e.g., English and French Canadians, First Nations, Asian, European, Jamaican, British). Annual family income categories ranged from under \$20,000 to more than \$100,000. Many families spoke more than one language but English was most commonly used. The variety and multiplicity of diagnoses attributed to the children revealed that most appeared to have very complex presentations and multiple challenges. A single diagnosis of developmental disability was rare. Examples of the many diagnoses for the children included: Autism, Pervasive Developmental Disorder, Down syndrome, Fetal Alcohol syndrome, Fragile X, and Asperger syndrome.

Qualitative results

A modified grounded theory analysis, using a constant comparative method (Strauss & Corbin, 1990), was employed. This approach to qualitative data analysis necessitates a number of steps that included: (a) transcription of the

audiotapes; (b) listening to the audio-taped interviews; (c) reading the transcripts; (d) preliminary coding of transcripts; (e) development of codes and an overall system for coding the data; (f) application of codes; (g) identification of higher-level themes and concepts; and (h) development of the emergent conceptual framework.

The qualitative data produced a rich set of interrelated concepts and themes. Only selected, key emergent themes, concepts, and supporting quotes from participants are presented here. Eleven major themes, each with a number of sub-categories, were identified in the initial qualitative data analysis. Based on further analysis of these themes, a conceptual framework of parents' perspectives regarding the quality of life for their children having developmental disabilities was developed.

The data analysis indicated some broad, fundamental principles. Specifically, the various aspects of quality of life for children in the three age sub-groups of interest were essentially the same. However, different aspects of quality of life were more important at different times in children's lives, between the ages of 3 and 12 years. For example, enjoying good relationships with peers is more important for a 12-year-old than a 3-year-old. In addition, the child's quality of life and her/his family's quality of life are seen by parents as interconnected. Finally, to a considerable extent, the child's quality of life is dependant upon others in her/his life (e.g., parents, siblings, peers, teachers, professionals, and community members).

The fundamental elements of quality of life are: (a) the child, (b) her/his parental and family environment, and (c) the broader environment (e.g., neighbourhood, community, school, and other institutions such as governments whose policies affect the lives of these children and their families). These three elements are in ongoing, interactive, and dynamic relationship. The child contributes his/her needs, personal resources, attitudes, and expectations. The parents and family contribute (or do not contribute) resources and supports and hopes and expectations for the child. They also bring their needs, attitudes, expectations, and understanding of their own and others' responsibilities. The broader environment consists of the child's school program, community, professionals who provide services, and political structures. Collectively, this broader environment contributes (or does not contribute) physical, financial, emotional supports, resources, policies, expectations, and attitudes. This environment also makes demands of the child and her/his family. An assumption of the model developed is that the better the fit or overlap among these three elements, the better the child's

quality of life will be. Conversely, a poorer fit (i.e., a smaller degree of overlap) among these elements results in a poorer quality of life for the child. In essence, the overlap of these three elements constitutes the child's quality of life. As one parent summed it up: "...quality of life means to me giving them the best that you can give them, whether that's financially, mentally, emotionally, physically, spiritually, in any form of life, just giving to them, the maximum that you can give them."

The data analysis also revealed three major domains or aspects of quality of life that emerge from the ongoing relationship among the child, his/her parental and family environment, and the broader environment. These domains are (a): Being -- who the child is perceived to be; (b) Belonging -- the child's connections to people and places; and (c) Becoming -- the child's nurtured growth and development.

Some sample verbatim quotes are presented to illustrate some of the ideas parents expressed about these aspects of their children's lives. The notation ... within a quote indicates missing words. The use of square brackets indicates a word inserted by the authors to better convey the meaning of the transcribed quote.

The Being part of the child's life will be good to the extent that the child is seen and treated by others first and foremost as a child rather than simply as "a disability." The child is considered and treated as part of his/her family and community. For example, one mother said, "...they both [two male relatives] treat him like he's a boy. They rough-house. They wrestle. They toss him around. They physically play with him, the way they would with any small child...and they treat him like he's a kid." In contrast, one parent spoke about how readily the child can be seen as "a disability": "...when you get a diagnosis, as devastating as a lifetime disability... you tend to see the disability and the child disappears for a while. And sometimes they disappear forever..."

The Belonging aspect will be good to the extent that s/he has a safe and secure environment, is understood by others, has positive interactions with important others (e.g., family, friends, teachers), and there is a good fit between the child and her/his environment. For example, one parent emphasized the quality of the child's connections with others and with places: "To go out in the world makes him happy, you know, and to go to school and to go to these play groups, to be with people and [at] playgrounds, you know. That makes him happy."

The Becoming part of the child's life will be good to the extent that the child's current major needs have been identified and are being accommodated and that important others' expectations (e.g., parents, family members, teachers) are well-matched to the child's abilities. One of the parents interviewed emphasized the importance of meeting her child's present needs so that he can continue to develop: "Will he get married? I don't know. Will he, um, have his own place? I don't know. But what I want for him is to give him the best now so that he can reach his best potential when he's older and I don't know what that's going to be." Another parent clearly addressed the issue of a good match between her child's abilities and others' expectations: "...I don't like to see her 'baby-fied' because she's not a baby. And when you 'baby-fy' somebody, you aren't going to give them what they need because you turned them into something that's going to be totally unacceptable when she grows up."

Discussion

The conceptual framework presented here is significant for several reasons. First, it is relevant to the child's life as whole, rather than addressing specific deficit areas. As one parent put it: "You know, just because he is disabled doesn't mean he can't have a good life." Accordingly, the framework goes beyond this narrower scope of medical and health concerns to encompass how others perceive and treat the child and her/his connections with important others (friends, parents, siblings, relatives, teachers, professionals) as well as the fit between the child and her/his environment. In addition, it is concerned with how well her/his needs have been identified and accommodated and continue to be and how well others' expectations of the child match his/her abilities. Second, it captures the complex nature of the quality of life for this group of children. Third, it reflects the voices of parents who, at this stage of their children's lives, have considerable insight into what contributes and detracts from their children's quality of life. The relevance of this new conceptual framework beyond the parents whose voices it reflects is currently being assessed. This assessment is being conducted in the context of a validation study of an instrument, based on the framework outlined here, which has been developed to measure parents' perspectives of their children's quality of life (Renwick, Fudge Schormans & Zekovic, 2003).

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Integration of Children with Developmental Disabilities in Social Activities

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Abstract

The current study examined the integration of children (n=35) with developmental disabilities (DD) in social activities, the supports received, and caregiver satisfaction with supports. Caregivers completed measures of demographic information, the AIMS interview, and the Child Behavior Checklist (CBCL). Results indicated that 97.1% of children were integrated according to the AIMS acculturation framework, as their needs were identified and supported in a way that facilitated their participation in community activities. Although children were receiving support in social activities, the majority of support was provided by caregivers and paid workers. Whether interaction only with other adults should be considered social integration and directions for future research are discussed.

Parents and advocates of social and educational inclusion argue that opportunities for interaction are essential if social integration is to take place (Center, Ward & Cecily, 1991; White & Dodder, 2000). In addition, recent research has highlighted the benefits of integration for children with developmental disabilities (DD) (e.g., Cook, 2001; Odom, 2000). However, achieving social integration for children with DD involves more than merely providing these children with opportunities to interact with nondisabled peers.

Many children with DD have difficulties in creating and maintaining peer relationships. For instance, children with DD often have behavioural difficulties that can result in experiences of academic failure and impaired peer relations (Merydith, 2001). Furthermore, many children with DD have trouble with communication skills. Communication lags can become increasingly apparent as children age and may have a negative impact on the

development of friendships (Hall & Strickett, 2002). As a result of these and other problem areas, children with DD often require external supports to facilitate any participation in social activities.

Recent research concerning the social interactions of children with DD has focussed on the nature of their social activities. For example, a study by Hall and Strickett (2002) found that half of the children with DD in their sample spent more time interacting with adults than typically developing same-aged peers during free time periods at school. Children with DD were found to experience difficulties in creating and maintaining peer relationships, both with children with or without disabilities. Geisthardt, Brotherson and Cook (2002) found that children with disabilities are often perceived as less socially competent and of lower social status, and that children with behavioural problems and significant cognitive limitations spent the least amount of time with playmates at their homes of all children studied. Many parents of children with DD, in this study, felt that other parents were hesitant to encourage interaction between their child and a child with a disability because of the extra attention and supervision that children with DD require.

Integration for purposes of this study was considered as acculturation (Minnes, Buell, Feldman, McColl & McCreary, 2002). This view of integration is that children have their needs identified and supported in a way that facilitates their participation in broader community activities. Odom's (2000) idea of integration is similar. He explains that the key in educational integration is to place children with disabilities in inclusive classrooms, while simultaneously supporting their special needs.

The current study explored the integration of children with DD in social activities, factors facilitating and impeding participation, and caregiver satisfaction with supports provided to their children in social activities.

Method

Participants

Participants were 35 caregivers of children with DD (5 males; 30 females, $M = 43.94$ years, $SD = 8.47$). The children included 7 females ($M = 14.07$ years, $SD = 3.60$) and 28 males ($M = 11.16$ years, $SD = 4.04$) ranging in age from 6-18 years. Participants were obtained through the South Eastern

Ontario Geographic Registry in Developmental Disabilities (GRIDD), Extend-A-Family, Queen's University Mental Health Team in Developmental Disabilities in Kingston, and informal contacts.

Materials

1) *Demographic information*. Caregivers of the participating children with DD filled out a short questionnaire that indicated the age and gender of their child and their child's formal diagnosis, as well as their own age, education level, and type of employment.

2) *Child Behaviour Checklist (CBCL)*: Achenbach & Rescorla, 2001). The CBCL was used to examine behaviour profiles of the children as reported by their caregivers. Data was collected on 118 problem items, yielding standardized Internalizing, Externalizing, and Total Problem Behaviour scores. Although the CBCL has been standardized on children without disabilities, recent findings have found the CBCL also to have adequate psychometric properties when used with children with DD (Berman, Solish, Nachshen & Minnes, 2002).

3) *AIMS Interview-Child Version* (Minnes et al., 2002). The AIMS Interview measures community integration from an acculturation perspective. Based on whether needs are identified and supported in a way that facilitates community participation, an individual can be considered either Assimilated, Integrated, Marginalized, or Segregated. (For a more complete explanation of the AIMS Interview, see Minnes et al., 2002). The AIMS interview has been shown to have sound psychometric properties including concurrent, content, and construct validity when used with adults with DD (Minnes et al., 2002). The current study expanded the use of this measure for use with children, after a pilot study demonstrated good face and content validity as well as inter-rater reliability (.92-.97).

Procedure

The caregivers of children with DD voluntarily participated in a one-hour telephone interview with the researcher. All participants completed the measures listed above, and were ensured that any information provided was confidential.

Results

The majority of children in this study, 97.1% (34/35), were rated by their caregivers as Integrated in social activities, meaning that their disability-related needs were identified and supported in a way that facilitated involvement in the community. Only one child (2.9%) was rated as Marginalized, meaning that she did not participate in any social activities. No children were scored as Segregated on the Social domain, (i.e., no children were involved exclusively in social activities with three or more people with disabilities). Finally, no children were rated as Assimilated in social activities, meaning that all children who did participate in social activities received support in some capacity.

Although the children were rated as socially Integrated, it is important to consider who is providing support and who is including them in social and community activities. Caregiver ratings of satisfaction with supports in the Social domain received a mean score of 4.07 out of 5, indicating that a majority of caregivers were "Mostly" satisfied with the support their children were receiving in social activities. Nevertheless, it is important to note that 48.6% (17/35) of children received support in this area from their caregivers exclusively, and at least 34.3% (12/35) of caregivers reported that they and a worker provided the support for their child.

Furthermore, according to a question on the CBCL asking how many close friends, excluding brothers and sisters, a child has, it appears that the children in this sample were not as well integrated as suggested by the AIMS findings. In fact, according to caregiver reports 45.7% (16/35) of children had no close friends, 8.6% (3/35) of children had one close friend, 20.0% (7/35) had two or three close friends, 22.9% (8/35) had four or more close friends, and one parent reported that since her child was nonverbal she could not judge how many close friends he had. Furthermore, examining the number of hours that the children spent with their friends outside of school hours, again they seem not to be adequately socially integrated. In this analysis 45.7% (16/35) of children spent less than one hour a week, 20.0% (7/35) spent 1 or 2 hours a week, 17.1% (6/35) reported spending three or more hours, and 17.1% (6/35) said that this question was not applicable because their child had no friends. Finally, results of a correlational analysis showed that the number of friends a child has is negatively correlated with the Externalizing problem behaviour subscale on the CBCL ($r(34) = -.360$, $p = .036$).

Discussion

The results of this study are positive in that 97.1% of the 35 children of participants were rated as Integrated in the Social domain of the AIMS interview. This finding implies that the needs of these children in social activities, such as club participation, shopping, and sporting events, were identified and supported in a way that facilitated community participation. However, a closer examination of the data regarding those involved in social activities with these children yields less optimistic results.

It is important to distinguish between physically integrating children with DD and socially integrating these children. Physical proximity alone does not ensure that students with DD will actually be included socially in peer activities and interactions. Many studies have shown the benefits of having friends. It has been said that friendships and relationships in childhood serve many functions that can contribute to quality of life, and support opportunities for social development, companionship, intellectual growth, and social support (Geisthardt, Brothers & Cook, 2002). For children without disabilities, especially as these children become adolescents, many of their social activities include friends. Normally developing children begin to label one another as friends in preschool and by the time they finish elementary school they have developed close and personal friendships (DeHart, Sroufe & Cooper, 2000). However, the study by Geisthardt et al. (2002) illustrated that of 28 children with disabilities 14 rarely or never had neighborhood peers over to play. The present study showed that 16 children did not have even one close friend with whom they could engage in social activities. Although children scoring Integrated in social activities may appear to be included in social activities, closer analysis indicates that they may not have been receiving the same benefits from social interactions as their peers.

The present study also illustrated how problem behaviours can affect peer interactions, as there was a relationship between having higher externalizing problems and fewer friendships. It appears that children who are outwardly difficult to get along with may be rejected by normally developing and other disabled peers.

Although caregivers in this study reported relatively high satisfaction with supports for their child in social activities, with an average score of "Mostly" satisfied, more careful examination of the data raises additional questions. Of the 34 children who scored Integrated in the social domain, 16 caregivers reported that they were the ones providing the support needed for social

activities to occur, and an additional 12 caregivers reported that the support was provided only by them and paid workers. Thus, in the majority of cases, the caregivers' satisfaction rating of the support offered to their children in social activities was actually a measure of how satisfied they were with the support that they themselves provided, as opposed to support received from peers or from recreational and activity coordinators. Whether the caregivers would feel as satisfied with the social support provided to their child by individuals other than themselves requires additional research.

Deeming a child or adolescent who interacts in social activities exclusively with parents and paid workers as integrated socially appears problematic. Because this study was only exploratory, conclusions would be premature. Nevertheless, we believe that it is a first step in exploring the full nature of integration of children with DD in social activities from an acculturation perspective.

Further research will be conducted to obtain larger samples controlling for factors such as gender and age of the child with DD, as well as caregiver characteristics such as age, gender, and marital status. The *AIMS Interview Child Version* is also being expanded to obtain more in-depth information about children's social activities and the supports that are provided by family members, friends, and workers in each activity. In addition, more detail regarding caregiver satisfaction with their child's social activities and supports will be gathered.

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