

Family Quality of Life When There Is a Child With a Developmental Disability

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Abstract The conceptualization of individual quality of life is reasonably well established, and now family quality of life and intellectual disability is emerging as an important field of study. This article examines comparative family quality of life in three types of families: those with a child who has Down syndrome, those with a child with autism, and those of similar household composition but without a child with a disability. Data were collected using the Family Quality of Life Survey, which was sent to participating families, and by interviews with selected families on a follow-up basis. Data from the 3 groups were analyzed in terms of quantitative and qualitative information. The needs and choices of families were contrasted in terms of the child's diagnosis. Findings showed that families' satisfaction and needs varied within the 9 quality of life domains assessed, raising questions of support and care and the ability of families to pursue desired goals. The authors suggest that there is a need to both identify and provide measures of care and support that would enable families to function at an optimum level within their home and community, so they may experience a quality life similar to that of families without a child with a disability.

Keywords: autism, Down syndrome, family quality of life

INTRODUCTION

Family quality of life has become an area of increasing interest in recent years (Aznar & Castañón, 2005; Turnbull, Brown, & Turnbull, 2004). This development closely follows expressions of quality of life concepts within the field of intellectual disabilities. It is reasonably well established that there are a number of domains or areas that impact either positively or negatively on an individual's quality of life (Felce & Perry, 1997), and aspects of quality of life in this field have been discussed by authors at both the conceptual (Schallock et al., 2002) and practical levels (Brown & Brown, 2003). As the quality of life approach continues to develop, more attention has now turned to family quality of life. It is recognized that family issues around the person with a disability have been studied and reported previously (e.g., Baxter, 1987; Gray, 2002; Hayes, 1996); however, studies of family quality of life that sensitize us to a wider concept of family and the issues that occur when there is a child with an intellectual or developmental disability have just begun to emerge. As Turnbull et al. (2003) have noted, much of the family and disability literature

focuses on the issues of the child with a disability within the family, and frequently the mother as primary carer becomes deeply concerned with and focused on the life of the child with an intellectual disability. This means that the family may lack balance and may be affected by the sequence of events surrounding the interaction with the family member having a disability. Such effects are not necessarily negative, but there is a wide range of challenges that face families in these situations. Family quality of life studies attempt to explore how various domains of life are impacted when there is a child with a disability, and what are the perceptions of family members about family life in general. Such studies also explore the effects of services and community, as well as examine the influence of each individual family member on the family as a whole. It has been suggested that the same major principles of quality of life (see Schallock et al., 2002) may also be relevant to family quality of life, and these have been employed in the development of the survey instruments.

Family quality of life has become an area of increasing interest because of the wide range of concerns that are being reported by parents in many studies. The development of quality of life concepts, which provide opportunities for a new approach toward disabilities and focusing on the broader environmental impacts and contexts of life, underscores the importance of now applying these concepts to the area of family quality of life (see Brown & Brown, 2003; Turnbull et al., 2004). Over the past 50 years or so, there has been a movement to deinstitutionalize people with

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intellectual disabilities and support them in the community with their parents or in residential community-based units of various kinds. This often means that parents, particularly mothers, become the primary carers and supports of a child with an intellectual disability on an intensive basis, which impacts family behavior and lifestyle. This gives rise to a number of issues, and although there is considerable support for inclusion of individuals with intellectual disabilities in the community, challenges arise for families. The important questions being asked are: (1) how does the family function under these circumstances? and (2) what are the current concerns and needs of the primary carers and other members of the family? The current approach to family quality of life (see Brown & Brown, 2003) provides, through both its structure and the survey tool methods used to gain useful information on this topic, necessary data for model building in terms of policy and directions for practice in the community.

Cummins (2001), among others, has commented on the "gold standard" in reports on quality of life. Individuals are likely on average to report a satisfaction index of 75% of maximum on a scale of 0–100, in which 100 represents maximum quality of life (Cummins, Eckersley, Pallant, Van Vugt, & Misajon, 2003). This tends to occur despite widely varying circumstances. In the literature besides that specifically addressing intellectual disabilities, this is not always the case (see James, 1997). However, in the field of disability, these types of reports have given rise to dilemmas in measuring family quality of life. If such a high percentage of families report satisfaction regardless of circumstances, this may give rise to misleading information regarding service success and needs for change in direction or practice. This is an issue discussed later in this article.

It also seems appropriate to look at how different types of intellectual disability may affect families (Hassall, Rose, & McDonald, 2005; Gray, 2002). For example, the work of James and Brown (1992) concerning Prader Willi syndrome, Krauss, Seltzer, & Jacobson (2005) in relation to autism spectrum disorder (hereafter referred to as autism), and Hayes (1996) in relation to Down syndrome, indicate that there are probably different challenges and stresses in relation to family lifestyles contingent on the nature of the disability of the child (Hastings, 2002). This article explores the differences and similarities in family quality of life for families with a child with Down syndrome and for those with a child with autism.

As noted by Brown, Bayer, and Brown (1992), quality of life research focuses on the interaction between an individual and the environment, and specifically explores individual well-being by examining factors, such as family situation, social supports, leisure activities, spiritual values, career opportunities, and economics. Quality of life is defined by how an individual interprets the environment and how the individuals and groups he/she references to affect his/her well-being. It is an individual's personal interpretation (Schalock et al., 2001). Consequently, the issues addressed in this article are based upon the perceptions of the individual who is reporting about family quality of life. We acknowledge that, although others may perceive various aspects

of life that impinge on the family differently, it is the family's own perception that motivates behavior. The first aim of the article will be to describe family perceptions of quality of life as viewed by the primary carer(s). Although it is desirable that all family members respond to their individual perceptions of family quality of life, the responses from the primary carer, such as the mother, are much more readily obtained and also reflect the issues that the primary carer is dealing with in relation to the family. In this study, although the mother is the most common respondent, the data are directed specifically to family issues and family concerns.

The questions addressed in this study included:

1. What are primary carers' responses to the Family Quality of Life Survey and how do they relate to the domains of family quality of life?
2. In what ways is family quality of life in the three family groups similar to or different from each other?
3. Are there differences in terms of family perceptions of services and do these relate to family quality of life?
4. How do respondents perceive satisfaction within the domains of quality of life?

METHOD

Procedure

The sample population in this study included families with a child with selected developmental disabilities in British Columbia, Canada, specifically children with Down syndrome and autism, who were between the ages of 3 to 13 years. An initial letter describing the study was mailed to those families defined within the sample population, along with a request for their participation and accompanied by a self-addressed envelope in which to return this request. Organizations working with the defined population, such as the Down Syndrome Research Foundation in Vancouver, B.C., and additional community groups in Victoria, B.C. supported this process by mailing out information and inviting the first two authors to a number of community meetings to discuss the study. The community meetings in which the study was discussed with potential participants proved to be an invaluable means of both increasing the families' interest in the study and identifying the defined sample.

If the primary carer expressed an interest in participating in the study, the Family Quality of Life Survey was mailed, along with two consent forms and a self-addressed return envelope. To support this process, a follow-up phone call was made around the time the survey was mailed to facilitate a higher rate of return. The participants were also asked to indicate whether they would be interested in a follow-up interview and, if consent was given, a face-to-face or telephone interview was conducted. Ethics approval at the University of Victoria and the relevant ethics committees of the local organizations concerned was obtained prior to the implementation of this study.

Instruments

The Family Quality of Life Survey (Brown, Neikrug, & Brown, 2000) was the main instrument used. In brief, the survey consists of 10 areas, nine of which represent specific domains that influence family quality of life (see Table 2). The domains are ones that are generally accepted in the quality of life literature (Schalock et al., 2002) and have further been used in the literature on family quality of life (Turnbull et al., 2003). The first area requires the participant to define his/her family composition and experience. The remaining nine areas primarily utilized a four- or five-item Likert scale. However, some questions required a written explanation. In this report, we discuss the quantitative findings of this study, with the accent on family satisfaction in the nine domains. The instruction to respondents of the survey was to consider the whole family. It should be noted that the satisfaction with family quality of life in each domain is the final question in the domain after other questions concerning the nature of the family's involvement in the particular areas concerned have been asked. So the final question is one in which sensitization to the content of the domain being investigated has already taken place.

Qualitative information gleaned from the surveys, and the interviews are used to illustrate the survey's quantitative findings.

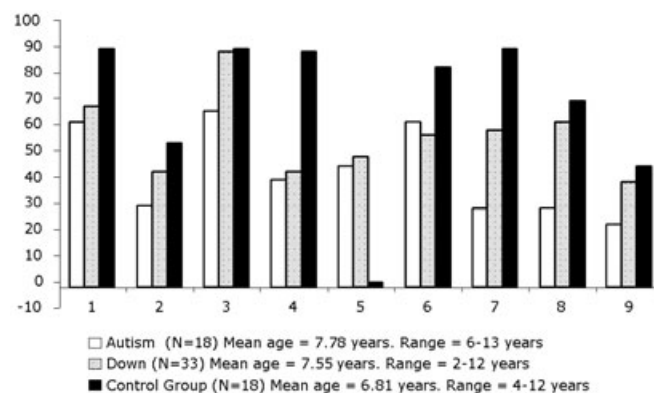
Sample

Invitations to participate in the study were made with the support of the Down syndrome and autism organizations in the Vancouver and Victoria areas of the province of British Columbia, Canada. Only a small percentage of the families notified responded. In addition, several families invited themselves into the study although they had not directly received an invitation. Thus the samples were essentially self-selecting and should be regarded as a convenience sample. However, they did meet the criteria of children's age range and disability type. Overall, 51 surveys were returned from families who met the criteria of children's age range and disability type ($n = 33$ with Down syndrome; $n = 18$ with autism). Ten from the autism group and 16 from the Down syndrome group agreed to a follow-up interview, which was carried out at the individual's convenience. All the children in the two disability groups were professionally diagnosed through professional services involving pediatric and/or psychiatric consultation plus psychological evaluation.

Data on 18 families who had similarly aged children but who had no child with a disability in the family were also obtained. Details of children's ages in each group are given in Figure 1. The mothers' ages in the three groups were very similar (mean age in the three groups lay between 38 and 40 years), while the fathers' mean age range was more disparate (between 41 and 45 years); the highest mean ages were observed in the Down syndrome group. Composition of families showed a median score of 4 in each group, ranging from 2 to 7 overall.

FIGURE 1

Percentage of respondents who are satisfied or very satisfied with family quality of life for each domain (autism, Down syndrome, and control group). Domains: (1) Health; (2) Financial well-being; (3) Family relations; (4) Support from other people; (5) Support from disability-related services; (6) Spiritual and cultural beliefs; (7) Careers and preparation for careers; (8) Leisure and enjoyment of life; and (9) Community and civic involvement.



RESULTS

The results are presented in order of correlations, analysis of variance and allied tests, and percentage responses using rating categories on the Likert scale.

Correlations

Correlations between each of the nine domains and the summed family quality of life results are presented in Table 1 for the two disability groups. Arithmetical adjustments were made so that, separately (1) Likert ratings and (2) domains were equally weighted in the ensuing analyses and, thus, contributed equally to the full family quality of life totals. We have no conceptual and empirical evidence, at this stage, that one domain is more relevant or contributes more than another to family quality of life.

In the autism group, five of the nine possible correlations are statistically significant at or beyond the 0.05 levels on a two-tail test, in terms of their association with overall family quality of life as measured by this survey. Seven of the nine correlations are statistically significant in the Down syndrome group. Four of these domains are held in common with the autism group. The lowest and insignificant correlation in both groups was associated with the domain of support from disability-related services.

Domain Differences Among the Three Groups

Univariate analysis of variance shows highly significant statistical differences among the three main family groups

TABLE 1
Correlation between each domain and total of family quality of life (FQOL) by autism and Down syndrome groups

Domain	Down	Autism
	FQOL (<i>n</i> = 27)	FQOL (<i>n</i> = 17)
Health	0.673**	0.546*
Financial well-being	0.410*	0.454
Family relationships	0.610***	0.787***
Support from other people	0.684**	0.377
Support from disability-related services	0.300	0.239
Spiritual and cultural beliefs	0.325	0.762***
Careers and preparing for careers	0.572**	0.731***
Leisure and enjoyment of life	0.821***	0.458
Community and civic involvement	0.495**	0.483*

Numbers differ from total sample due to absence of responses on some questions.

*Significant at or beyond 0.05 level (two tail).

**Significant at or beyond 0.01 level (two tail).

***Significant at or beyond 0.001 level (two tail).

($F_{2,66} = 17.45, p < 0.001$). Post-hoc tests indicate that this significance lies between the Down and nondisability or control group ($p < 0.001$), and the autism and control group ($p < 0.001$). An examination of mean differences between family quality of life domains was undertaken via multiple analysis of variance. There is a significant group main effect of the independent variable (Wilks' lambda = 0.509, $F_{16,112} = 2.81, p < 0.001$). The omnibus F -tests show significance for the following dependent variables: health ($F_{2,63} = 9.25, p < 0.001$), financial well-being ($F_{2,63} = 4.34, p < 0.05$), family relationships ($F_{2,63} = 14.28, p < 0.001$), careers and preparing for careers ($F_{2,63} = 7.56, p < 0.001$), and leisure and enjoyment of life ($F_{2,63} = 4.83, p < 0.05$). Post-hoc F -tests of group differences were used to determine which group means differed significantly from others. Tukey tests show that for health, the control group differs significantly from the Down syndrome ($p < 0.01$) and autism groups ($p < 0.001$). For the domain of financial well-being, the control group also differed significantly from both Down and autism groups ($p < 0.05$). For support from other people, the difference lay between the Down and control groups ($p < 0.001$) and between the autism and control groups ($p < 0.001$). For the domain of careers and preparing for careers, the control group differed from the Down ($p < 0.05$) and autism groups ($p < 0.001$); and for the domain of leisure and enjoyment of life, the difference lay between the autism and control groups ($p < 0.01$), but not between the Down and control groups ($p > 0.05$). Significant differences favor the control or nondisability group.

TABLE 2
Down syndrome, autism, and nondisabled (control group) families that are satisfied or very satisfied with their family quality of life for each domain

Domain	Down	Autism	Control group
	<i>n</i> (%) Total 33	<i>n</i> (%) Total 18	<i>n</i> (%) Total 18
Health	22 (67%) (33)	11 (61%) (18)	16 (89%) (18)
Financial well-being	14 (42%) (33)	5 (29%) (17)	9 (53%) (17)
Family relations	29 (88%) (33)	11 (65%) (17)	16 (89%) (18)
Support from other people	14 (42%) (33)	7 (39%) (18)	15 (88%) (17)
Support from disability-related services	15 (48%) (31)	8 (44%) (18)	NA
Spiritual and cultural beliefs	17 (56%) (30)	11 (61%) (18)	14 (82%) (17)
Careers and preparation for careers	19 (58%) (33)	5 (28%) (18)	16 (89%) (18)
Leisure and enjoyment of life	20 (61%) (33)	5 (28%) (18)	16 (69%) (18)
Community and civic involvement	12 (38%) (32)	4 (22%) (18)	8 (44%) (18)

Perceived Overall Family Quality of Life Satisfaction Within Domains

Table 2 and Figure 1 show the percentages for satisfied and very satisfied respondents combined for each domain in terms of perceived family quality of life for all three groups separately (Down, autism, no disability). In the Down syndrome group, four domains showed percentage satisfaction below 50%, and in the autism group, six domains fell below this cut-off point. In the families without disability, the disability service domain is not relevant, but of the remaining eight domains, only one fell below the 50% satisfaction level (community and civic involvement). Of the respondents, 44% of the autism group were satisfied with support from disability-related services (no respondent was very satisfied), and 48% of the Down syndrome respondents were satisfied or very satisfied in terms of support from disability-related services. The domain, support from other people, also returned low levels of respondent satisfaction in both groups, and this was also true of the domains of financial well-being and of community and civic involvement. In the autism group, the domains of leisure and enjoyment of life and of careers and preparing for careers also fell well below the 50% level in terms of satisfaction.

BOX 1

Comments of mothers with respect to obtaining respite supports.

Mother (Down group): "We were on the respite list for 7 years before we got it."

Mother (autism group): "I can't plan for things. I would like to go back to school. More respite."

Mother (autism group): "I would be happier . . . having free time and being a person . . . I could go to school and take night courses . . . I am trapped that is how I feel."

Mother (autism group): "Respite . . . obstacle for Mom doing anything like school or work . . . even for husband to go back to school."

In terms of statistical analysis, there are significant differences in terms of quality of life satisfaction between the Down and autism groups on careers and preparations for careers ($\chi^2(1) = 4.15, p < 0.05$) and leisure and enjoyment of life ($\chi^2(1) = 5.02, p < 0.05$). These differences represented higher satisfaction in the Down syndrome families compared with the autism group.

Other percentage data selected as relevant to this article are those associated with the four highest correlations for the combined groups in which correlations are all in the 0.6 or above bracket. These are, from highest to lowest correlation, family relations, leisure and enjoyment of life, careers and preparing for careers, and health. The other domain with a high correlation, but only in the autism group, is the domain of spiritual and cultural beliefs ($r = 0.762$). In terms of family relationships, the perception of the primary carer was that trust and sense of belonging in a family was high, although around a quarter (24% of the Down syndrome families and 29% of the autism families) had hardly any or only little opportunity for family activities. Seventy-eight percent of the Down and 82% of the autism families, respectively, felt that they received hardly any practical support from friends and neighbors. Leisure and enjoyment of life was a further concern, with 22% of the Down syndrome families and 35% of the autism families having little or no leisure. Fifty-three percent and 69% of Down and autism families, respectively, put this down to lack of adequate respite opportunities, but the issue of respite came up in relation to a wide range of issues relating to support (e.g., education and career of parents). In terms of careers and preparing for careers, 31% of the Down syndrome group families and 29% of the autism group families stated that they had to give up the pursuit of education, and 31% the Down families and 41% of the autism families stated that the primary carers could not prepare for careers or have the careers they wanted (see Box 1).

Although general family health was seen as high in most families (92% for Down and 94% for autism groups), 11% of the Down families and 41% of the autism families perceived that they had hardly any or no activities to maintain or improve family health. Spiritual and cultural activities were important for many families (73% of the Down and 88% of the autism families felt

that spiritual and cultural beliefs were somewhat to extremely important in guiding the way they think and act).

DISCUSSION

The families without a child with a disability showed statistically significantly higher levels of satisfaction across all domains (with exception of the disability services domain). The nondisability group lay mostly in the 80% to 89% range of satisfaction, consistent with Cummins's (2001) concept of homeostasis. The importance of including families without a member with a disability as a reference group in studies of well-being and family quality of life needs to be stressed. The discrepancies in satisfaction between families in which there are and in which there are no children with disabilities should be a major consideration for disability services. This can provide an important marker for the levels of community and family satisfaction expectations within a specific range of families (e.g., geographic area, size, and family income). This would seem a critical element in attempting to support families with a child who has a disability, so they may more nearly function as other families.

The results raise a number of interesting questions, although these should be reviewed with caution because sample size was small and limited and may have been biased as the data from the respondent population reflected those who wished to be involved. It is possible that the respondents are those families who are more likely to feel it important to contribute, and may well have been those with time to do so, perhaps reflecting their higher quality of life and thus making generalizations of the findings tenuous. In most instances, mothers were the respondents, which is common in this type of study, and it must be recognized that it is their perception of family that prevails. However, the demographic characteristics of sex, family size, and economic security are consistent with the general population of families who have children of the same age with or without disabilities. Further, the results generally fit patterns that might be expected. Family relations, leisure and enjoyment of life, career and career planning, and health were perceived as contributing the most to overall family quality of life, although significant correlations suggested that

other areas or domains were also important contributors. It seems likely that different aspects of quality of life contribute disproportionately across families because of interaction between family circumstances and values. This is consistent with individual variations found in other quality of life studies (e.g., Brown & Brown, 2005). It is an important issue in relation to family choices, funding directions, and delivery of support from disability-related services. The issue of changing and varied support indicates the importance of consulting and taking into account family perspectives and needs for the whole family.

The question arises as to how disability services might support family well-being (this means all of the disability services that the families have experienced, such as government, service agencies, and health education—whether private or public). The correlation between support from disability-related services and overall family quality of life is insignificant in both disability groups, and satisfaction is below 50%. Although this does not necessarily mean that help for the person with a disability was poor, qualitative responses suggest that there are major concerns. Overall, the service's contribution to overall family quality of life was not perceived as significant.

It seems pertinent to ask whether disability services should be encouraged to enhance overall quality of life for the family or to limit services to the person with a disability. There are reasons for believing a wider approach is necessary (Hassall et al., 2005). Stable and effective families, that is, those who are least apt to be dysfunctional, are likely to be those who enjoy a high level of family quality of life. In our study, it was apparent that overall family health was perceived as satisfactory in the majority of cases and was a significant area in terms of family quality of life. However, we observed other issues affecting the families that may be of concern. One dealt with the time that families had to address issues such as maintaining or improving family health, pursuing education and careers, and having time for leisure and enjoyment of life. This constraint in time raises concerns about maintenance of health within the family, an issue that has wide-ranging social and economic implications for service support and delivery. Turnbull et al. (2004) note that there is often an overriding focus on the child with an intellectual disability by the primary carer, perhaps to the detriment of other family members. Although there were few, but important, statistically significant differences between the Down and autism groups, there was a trend to more isolation and less time availability in the families where there is a child with autism (see Table 2 and the data on preparing for careers and available time for leisure and enjoyment of life). There also appeared to be more negative comments from the parents within the autism group when the qualitative interview information was examined.

It would seem appropriate to consider the need for support of family time for activities that involve the member with a disability, and also of time focusing on other family members, thus ensuring a balanced, psychologically and socially healthy family. The respondents were largely mothers, and it seems likely that this represents a particularly important area for them. The

present data suggest that greater and more regular respite at the discretion of the family primary carers is highly relevant. This has been a concern in many reports (e.g., Cho & Gannotti, 2005), but here the issue is broadened because it is seen as important in many aspects of family quality of life. Time should be made available for career and educational development, which are likely to result in families obtaining higher economic resources and greater satisfaction. Time for all family members to receive adequate attention and time, which are linked to overall family enjoyment and satisfaction, is important. Further, there is dissatisfaction about community and neighbor support. There is evidence of poor satisfaction of families in this area, with families feeling isolated. This also appears to apply in a number of instances to relatives outside the nuclear family.

The correlation between spiritual and cultural beliefs and overall family quality of life is significantly and positively higher ($p < 0.05$) in the autism group than among the Down families. Furthermore, this domain is also more significantly correlated with career planning ($p < 0.01$), family relations ($p < 0.01$), and financial well-being ($p < 0.01$) in the autism families than in the Down group. Conversely, leisure and enjoyment of life is less significantly correlated with overall family quality of life in the autism families than in the Down group, while in the Down group, leisure and enjoyment of life is more highly correlated ($p < 0.05$) with support from disability-related services. This is consistent with the very low level of leisure and enjoyment of life in the autism group and most likely represents a fundamental concern.

Two focal issues emerge from this study. One is that different domains of quality of family life may be more conducive to family quality of life in families with one type or degree of disability than another despite variations relating to family quality of life within groups. In the families where there is a child with autism, it would appear that the difficulties associated with this prevent or inhibit career planning and development in many families (as noted in Table 2). It is of interest that the family financial earnings were lower in the autism group compared with the Down and nondisability groups. Among intact families, both parents worked in 53% of the Down group, while this was true in only 29% of the autism group. This may relate to the disturbing and disruptive behavior shown by children in the autism group (and this finding should be followed further), but it is consistent with the concerns shown regarding career development and preparation in this group. The domain of family relations is positive in most cases and judged particularly important for family quality of life, as is financial well-being (e.g., one mother's comment was "I am working 9 to 5 p.m., which gives me enough to pay the bills but not enough to do anything else."). High on the list of importance are spiritual and cultural beliefs for the families with a child with autism. It may be that spiritual and cultural beliefs become particularly important when other difficulties arise, including lack of personal time for the primary carer.

There is a second finding that is of importance. The percentage of individuals satisfied with the family's views in relation to

spiritual and cultural beliefs is very similar in both diagnostic groups, but it is in the autism families that the correlation with overall quality of life is higher than in Down syndrome families. The correlation in this domain between Down syndrome families and overall family quality of life is insignificant. The same type of argument can be applied to some other domains in the two groups. It would seem relevant, when interpreting family quality of life, to take into account both percentages of satisfaction and of dissatisfaction, as well as correlation of a domain with overall quality of life.

The qualitative information from respondents also indicates higher counts of negative quotes from the autism group. This seems consistent with expectations, as many of the parents in the autism group have to cope with behaviors that are extremely difficult to accept. It is also consistent with greater severity of conditions in the present autism group compared with the Down syndrome group, as described by respondents; for only 65% of the autism group are rated as mildly disabled whereas 89% of the Down syndrome group are labeled this way.

Family quality of life appears critically related to the amount of readily available respite, but it is not just in relation to the development of careers and further education or leisure and recreation for the family. The ability to leave the home to do the necessities of life is important and readily understood in terms of normal family functions. Going out of the home also creates challenges for the family and primary carer in particular. As three mothers in the autism group noted: "We do get respite but we use this time to do the cooking, cleaning and grocery shopping"; "The issues become more complex when there is more than one child in the family with a disability"; and given "the nature of autism . . . it is very hard to go anywhere with the kids."

Some parents raised concerns that they were informed that they were not eligible for respite support even though the family saw it as important for individual and family quality of life. As this type of concern is also appearing in data from other countries (Brown, 2006), it underscores the need to examine the extent and reasons that respite is necessary. The data also substantiate the importance of rapid response time in relation to need, whether, and to what extent families should have a say in determining what their needs are, and the degree to which support should be given. Within this context, the quality of life model, which is now accepted by many researchers and practitioners, underscores the importance of responding to perceived needs and identifying functional ways of meeting these needs.

There are other issues relating to respite but intrinsic to the extended family. They are issues that need to be addressed through wider family consultation with a skilled counselor. For example, one mother said that her child's grandmother "does not help out much with child care any more." This mother believes that this is directly related to her child's disability as her mother baby-sits her other grandchildren quite frequently. Other data (Brown, 2000) note the high level of requests for family carers and other members of the family to talk to their needs and their stresses, a concern that is also reflected in the current data.

Measure of Satisfaction: Is This a Sensitive Measure?

As indicated in the *Introduction*, it has often been noted that within any group of individuals, around 75% tend to indicate satisfactory quality of life. In our study, this was not the case, except for the nondisability control group. As noted in the *Results*, several domains of satisfaction recorded below 50% satisfaction. Even when the two groups were combined, this was true of five of the nine domains. Why should these results differ from previous ones in the quality of life literature? One possibility is that respondents were not just responding to their own satisfaction but for the family's as a whole. It seems possible that when responding about themselves, individuals tend to "put on a brave face," suggesting that all is well, but when considering others in their family, they give a more considered report. It is important to know whether this is the case as there has been a concern that despite high satisfaction responses from individuals suggesting that all is well, both the quantitative and qualitative results indicate that there is less satisfaction in a number of areas. Cummins (2001) suggests that individuals often move to a state of homeostasis at the satisfactory level of personal quality of life. Only when perceptual adaptation cannot be maintained because of environmental and personal circumstances do individuals report dissatisfaction. If this is correct, the current data that show low satisfaction in several areas of quality of life give rise to major concerns that need to be addressed.

There is at least one further possibility. The satisfaction domain questions were presented as the last question in each domain. This may have provided a response set that enabled respondents to consider satisfaction against the previous questions in the domain to which they had considered and responded. The ability to respond to satisfaction and quality of life within a context, which the respondent has immediately considered, may be a relevant issue in developing further family quality of life surveys, and warrants further research.

CONCLUSION

All the areas of family quality of life selected in this study proved to contribute significantly to overall family quality of life, with the exception of support from disability-related services. Some areas contributed more significantly than others, and this appeared to be associated with type of disability group. However, correlation should be used along with percentage satisfaction in each domain in interpreting responses. Different areas of family quality of life appeared to be relevant under differing circumstances. For example, severity or kind of disability and the support or lack of support may be seen as less or more relevant, depending on a variety of factors. Areas like spirituality that may be seen equally as important in terms of satisfaction in any two groups may be influenced by the challenges faced by a family. If they are considerable, then spiritual and cultural aspects of life may contribute more to overall

family quality of life, increasing the primary carer's stability and well-being.

We found that the satisfaction scores were much greater in the families where no child has a disability, yet the trend across domains appeared reasonably similar. It also appeared that in the two disability groups, satisfaction within a domain was not as high a value as has been suggested elsewhere. In our study, there was considerable dissatisfaction in several domains, and such concerns should be studied in greater depth, with consideration given to how these concerns might be addressed. Families raised concerns over a lack of sufficient support from disability-related services, especially with obtaining respite and gaining opportunities for career development and education among the primary carers. Although these indicators are based on small samples, they do raise important questions in relation to family quality of life.

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