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Challenged with Disability: Quality of Life of Arab Families in Israel

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Abstract

Background: Families that have children with disabilities face numerous challenges. In addition to the problems of accessing medical and allied health services and support, Arab families in Israel face unique challenges due to their status as a minority group with cultural traditions that differ from those of the predominantly Jewish population. This paper describes their family quality of life (FQOL) as they meet these challenges.

Methodology: The respondents were main caregivers of 96 individuals with disabilities among Arab families in Israel receiving disability services. The respondents completed the Arabic version of the *FQOLS-2006*, which operationalizes FQOL as a construct in nine domains of family life.

Results: The results reveal an underlying pattern within the domains that define FQOL. In general, the respondents demonstrated a fair sense of resilience and an ability to manage family challenges. The results suggest that families are satisfied with certain areas of their lives, such as family relationships, but experience difficulties in other areas of importance, especially in the area of support from professional disability service agencies.

Conclusion: The findings indicate the need for culturally sensitive input into the design, training process, and community relations during program development.

Given the importance of building and maintaining collaborative partnerships between Arab and Jewish professionals, further research is needed to develop application models for integrating this population into the Israeli service delivery system.

Introduction

There is a growing interest in family-centered approaches to services and support for families of children with disabilities. Having a child with a disability places a heavy burden on the family system. Children with disabilities require numerous services if they are to reach their potential. In addition to the medical and allied health services that these children require, almost all need assistance for academic difficulties and emotional problems as well.

The concept of family quality of life (FQOL) has been proposed as a means to assess the impact of support and services on families challenged by disability (Summers, et al., 2005). FQOL relates to the overall degree to which the family's needs are met, the extent to which families enjoy time together, and the extent to which they are able to do things that are important to them (Poston, et al., 2003). The emphasis on FQOL expresses recognition of the highly important role of families in maintaining the functioning and ongoing stability of all human societies (Brown & Brown, 2005).

Receiving needed services is a major challenge for many families, and difficulties in securing services further impinge upon their quality of life. Families who struggle to get treatment are often faced with a rigid and complicated bureaucracy, inconvenient service hours, and protracted waiting periods, as well as structural difficulties such as geographical distance and transportation problems. In addition, there is a lack of assistance in finding specialists and competent professionals, and in some cases there are no appropriate frameworks available for children with certain disabilities. Besides the challenges of accessibility to services, families raising a child with a disability often face severe financial hardship. The very struggle to get needed services is a strain on the family's often fragile financial

situation. If a child is ineligible for services, the family must pay for them privately. Even when the service is available and the child is eligible, the families are often required to make a high co-payment. Parents often must stop working or reduce their working hours, refuse opportunities for advancement with greater responsibility and salary, and delay their own continued education in order to care for their child with a disability (Strosberg, Sandler-Loef, & Naon, 2000).

Arab families in Israeli society

Beyond the distress that permeates all sectors of Israeli society as a result of war, terrorism, and political instability (Efrat, Ben-Arieh, Gal, & Haj-Yahia, 1998; Younes, 2007), Israeli Arab families face unique social, political, and cultural realities that affect their quality of life. Israeli Arabs currently comprise 19% of the population of Israel. They are marginalized from the dominant society due to their geographic, religious, and cultural differences. The Israeli Arab society is made up of many diverse elements, ranging from semi-nomadic tribal Bedouins and traditional villagers to Westernized city dwellers. This population is also divided by religion, with 82% Moslems, 9% Christians, and 9% Druze. Moreover, the Israeli Arab population is geographically divided as well, with 64% concentrated in the two northern districts. Despite the numerous differences within Israeli Arab communities, they are often perceived, especially by the Jewish population, as being a single cultural entity that is separate from the dominant culture.

These situations pose special challenges for Israeli Arab families that have children with disabilities that affect their interactions with the dominant society, especially in issues relating to the delivery of human services. This population experiences particular difficulties in accessing disability services (Tropp, Stout,

Boatswain, Wright, & Pettigrew, 2006). The predominant model of service delivery, which has been developed to serve the needs of the Jewish family, its culture and organization, is often at odds with the needs and culture of the Israeli Arab family (Ben-Ari & Azaiza, 1996; Wilf-Miron, et al.,2010; Wilf-Miron, Peled, Yaari, Vainer, Porath, & Kokia, 2011).

Family quality of life

Responding to the unique needs of Israeli Arab families requires knowledge of the extent and types of their needs and the ways in which the religious/cultural orientation of this community affects meeting those needs. Research provides evidence for the importance of a whole-family approach to assessment and intervention, which is culturally relevant and can be tailored to the unique needs of each individual family (Chack-Kie, Kwong-Leung, & Shengquan, 2011; Mottaghipour, Woodland, Bickerton, & Grant, 2006; Singh & Curtis, 2000). Research on family quality of life aims to make these assumptions a reality by describing family life, determining which aspects of family life contribute to and which detract from family quality of life, and suggesting how various aspects of family life can be improved to enhance overall family quality of life.

The Family Quality of Life Survey 2006 (FQOLS-2006) (Isaacs, et al., 2007) offers a useful conceptualization of family life, a method for measuring it, and for evaluating the success of supports provided to families. The Family Quality of Life Survey has been translated into 23 languages, and international interest in FQOL is reflected in the numerous research studies that have been conducted using its conceptual framework (Brown, Anand, Fung, Isaacs, & Baum, 2003; Brown, MacAdam-Crisp, Wang, & Iaroci, 2006; Isaacs, et al., 2007; Park, et al., 2003; Park,

Turnbull, & Turnbull, 2002; Poston & Turnbull, 2004; Poston, et al., 2003; Summers, et al., 2005; Turnbull, Brown, & Turnbull, 2004; Turnbull, Summers, Lee, & Kyzar, 2007; Wang, et al., 2004).

The purpose of this study was to determine the quality of life of the Arabic speaking rural families served by an agency northeast of Tel Aviv, to identify and evaluate the factors that enhance their family quality of life, and to integrate the FQOLS - *Arabic* instrument into the agency's service and evaluation repertoire.

Method

Procedures and participants

Respondents were clients of the Regional Family Advancement Center established at the Sindian – Beit Issie Shapiro Center in the Arab town of Qalansua, serving the Arabic speaking rural communities northeast of Tel Aviv. The objective of the center is to meet the special needs of the Arab families raising children with special needs in this area. This study was part of the Israeli Family Quality of Life Study, whose primary purpose was to gather preliminary data on the conceptual framework of family quality of life, using a unique combination of quantitative and qualitative methods appropriate to a whole-family approach.

The Israeli Arab Family Quality of Life study included 96 families with children with developmental disabilities. These families comprised a convenience sample of clients served by the Sindian – Beit Issie Shapiro Center. The sample consisted of 39 (40.62%) mothers of children with disabilities, 25 (26.04%) fathers, and 25 (26.04%) siblings, grandparents and others. The mean age of the children with disabilities was 13.46 years (range from birth – above 22 years, median = 11; see table 1 for age distribution).

- Table 1 here -

The sample included a wide range of diagnoses, including 29 (30.21%) with intellectual disability, 12 (12.5%) with Down syndrome, 10 (10.42%) with cerebral palsy, 9 (9.37%) with dual diagnosis, and the rest with other or mixed conditions. The mean age of the respondents was 41.39 years (range 23-61 years). Seven (7.29%) children were from single-parent families, and the rest were from two-parent families. In terms of the children with disabilities, 70% were males and 30% were females. No information was asked of respondents regarding the severity of the child's disability or regarding behavioral challenges

Instrument

The instrument used in this study, the FQOLS-*Arabic*, is a translation of the Hebrew version of the *Family Quality of Life Survey-2006*. The *FQOLS-2006* identifies the factors that contribute to improvement of the family quality of life (FQOL) of children with disabilities in Israel. It is based on the main concepts that underlie much of the general QOL literature (Cummins, 1997, 2005; Felce, 1997; Schalock, et al., 2002; Stark & Faulkner, 1996; Verdugo, Schalock, Keith, & Stancliff, 2005). These principles propose that QOL is: 1) multidimensional and influenced by many factors; 2) comprised of generally the same dimensions for all individuals, but that some aspects may hold more importance or salience than others for some individuals or groups; 3) has both subjective and objective elements; 4) is best studied using multiple methodologies; and 5) is studied for the specific purpose of improving life.¹

¹ Family Quality of Life Survey-2006 is described fully elsewhere (Isaacs, et al, 2007). For a full description of the core domains and the criteria that were used to select the final items that appear on the survey form the reader is referred to Brown, et al. (2006).

Nine core domains are included in the *FQOLS-2006*: health of the family; financial well-being; family relationships; support from other people; support from disability-related services; adequacy of values; careers and preparing for careers; leisure; and community integration. Each of these domains of family life was evaluated in terms of six dimensions that inform meaning: *Importance* – the importance of each domain to the family; *Attainment* – the amount of achievement in each domain; *Initiative* – the efforts of the family to increase attainment; *Stability* – the stability of attainment over time; *Satisfaction* – the satisfaction of the family with attainment; *Opportunities* – the perceived opportunity to increase attainment in the future. The responses to the items are rated on a five-point Likert type scale from lowest (1) to highest (5).

Two global questions were added at the end of the survey instrument to rate the family's global FQOL and overall satisfaction with their achieved FQOL. The respondents were the main family caregivers of the child with a disability and were interviewed by an Arabic speaker who also had a disability.

Instrument development

In the development of the *FQOLS-Arabic*, there was concern for the accurate transfer of concepts from one language to the other and from one culture to the other. The Arabic version was created by a trained social worker who is a native Arabic speaker, fluent in both languages, knowledgeable in both cultures, and not connected to the research team. The Arabic language translation was performed from the Hebrew version of the instrument and was completed on an item-by-item basis (Geisinger, 2003). The translated version was reviewed by a bilingual panel who shared the culture of the respondents in order to determine the degree to which the

domains were clearly understood and to ascertain that the terminology in Arabic was compatible with the original. The procedure adapted for the development of the *FQOLS-Arabic* is an often-used method for questionnaire translation and has certain advantages over the back-translation method (Brislin, 1970). However, the literature shows that there is no definitive method of translation which will manage all of the inherent problems (Acquadro, Conway, Hareendran, & Aaronson, 2008). The final instrument was found to be coherent and to have excellent overall reliability (internal consistency) (Cronbach Alpha = .923). There was no attempt at this time to analyze the factor structure of the instrument, as the instrument is based on the theoretical domains and dimensions developed in the literature.

Ethical Statement

Participation in the study was voluntary. Anonymity and confidentiality were protected by the following arrangements: Parents were approached to volunteer and participate in the study in the process of (but not contingent upon) their children receiving service. The data were collected by members of the research team who were not part of the treatment staff. No identifying information was asked on the survey forms, and the data were kept in a secure location in the research department away from the treatment units. The study was approved by the Helsinki Committee at Beit Issie Shapiro.

Results

Analyses were conducted using SPSS, version 19. Overall, the respondents reported a relatively moderate level of FQOL. The means of the nine domains shown in Table 2 range between $\overline{X} = 3.73$ for the domain of support from the family to $\overline{X} = 3.73$

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2.8 for the domain of quality of service from public agencies and adequacy of finances.

- Table 2 here -

Six dimensions inform the meaning of the FQOL domains, and the means of these six dimensions are shown in Table 3. The domains of Importance are rated highest for FQOL ($\overline{X}=4.37$), and a relatively high degree of Initiative ($\overline{X}=3.16$) is invested in improving the situation. However, in spite of this initiative, the degree of Attainment ($\overline{X}=2.95$) and the degree of Satisfaction ($\overline{X}=2.82$) are rated far lower. Similarly, the dimensions of Stability of FQOL ($\overline{X}=2.9$) and Opportunity for its improvement ($\overline{X}=2.64$) are assigned relatively low scores.

- Table 3 here -

Table 4 shows the results of the analysis of the nine domains of FQOL in terms of the Importance dimension. Financial importance received the highest score ($\overline{X} = 4.76$), while importance of support from others received the lowest score ($\overline{X} = 3.7$).

- Table 4 here -

The respondents' satisfaction with their FQOL is shown in Table 5. The data indicate that the domains relating to interpersonal relationships (Family, Community, and Others (i.e., friends and neighbors) were rated relatively highly (range $\overline{X} = 3.2$ -

3.71), as compared to the domains involving relations with institutions and agencies outside of the community ($\overline{X} = 2.02$).

- Table 5 here -

The attainment dimension was analyzed in terms of the core domains presented in Table 6. The respondents indicated that they had attained a fair degree of quality in their family life ($\overline{X}=3.78$) and a reasonable degree of good health ($\overline{X}=3.23$). On the other hand, they reported attaining considerably less in the other areas of FQOL.

The two global questions provide support for the findings of the multi-domain items. The respondents rated their family's global FQOL as reasonable (\overline{X} = 2.42, SD= .918) and their overall satisfaction with their achieved FQOL a little higher then reasonable (\overline{X} =2.73; SD = 1.13). The "Overall Satisfaction with FQOL" item was positively and significantly associated with the mean of the satisfaction dimension in all nine domains (r = .719, p < .01). The "Overall FQOL" item was positively and significantly associated with the means of the attainment dimension (r = .329, p = .001) and the satisfaction dimension (r = .719, p=.01) in all nine domains. The mean scores for the attainment dimension and the satisfaction dimension correlated positively with the respondents' overall evaluation of their FQOL: attainment with overall FQOL (r = .329, p<.01) and satisfaction with overall FQOL (r = .708, p< .01).

Two additional single-measure items included in the questionnaires referred to the level of satisfaction experienced by the respondents within the family. One item related to the respondents' satisfaction with the degree of responsibility that they carried for conducting the day-to-day affairs of the family. The second question

related to their satisfaction with the degree of responsibility that they personally assumed for the person in the family with a disability. The mean responses to these two items were $\overline{X} = 2.18$; SD = .876 and $\overline{X} = 2.00$; SD = .833, respectively. These results indicate that the respondents personally assumed considerably greater responsibility than desired in meeting both the general expectations for the family and the particular expectations for the person with a disability.

Discussion

Having a child with a disability places considerable stress on the family system. The aim of this study was to determine the quality of life of Israeli Arab families that have children with disabilities, as well as to identify and evaluate the factors that enhance their family quality of life. It was carried out as a part of the International Family Quality of Life Project, which initially consisted of researchers from Canada, Australia, Israel, and the U.S. and now includes researchers from more than 15 countries (Brown, 2012a; Isaacs et al., 2007).

In general, the findings show that the families in our sample tended to adapt to the problems presented by the special child without a significant negative impact on FQOL. This finding is similar to those of previous studies (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993). Support from family members and other relevant persons (i.e., friends and neighbors), as well as community integration, were rated as being of the highest importance to FQOL. All the other domains (i.e., financial, health, career, and leisure) were found to offer considerably less support, but were still rated as being highly important to the family.

Thus, family, friends, and others in the community provide the major sources of meaningful support to families who have a child with a disability. Moreover, when

we consider the degree to which the respondents were satisfied with their FQOL in the various domains, those of family, friends, and others in the community continue to be ranked comparatively high. These findings differ from previous research in Israel (Struch, et al., 2007), indicating that families with children with special needs are distrustful of informal community support for fear of stigma and exclusion.

Previous studies in Israel have also indicated the seriousness of the financial situation of families with a child with a disability (Strosberg, et al., 2000). Our data show that the highest score of importance ($\overline{X}=4.76$) was given to finances, yet a far lower score ($\overline{X}=2.16$) was accorded to satisfaction with finances. Health, career, and leisure were also rated very highly in terms of their importance – even higher than support from community or relevant others – however, they were rated considerably lower in terms of satisfaction.

Our findings therefore underline the discrepancy between the importance of the various domains for the respondents and their low degree of satisfaction with those domains. The general pattern indicated that despite the high importance of all nine domains to our respondents, many of the domains were rated as being relatively unsatisfactory. The exceptions to this were the domains in the informal system of family, friends, and others in the community. The formal system responsible for the provision of basic support (i.e., financial, health, career, and leisure) was viewed as being unable to provide such supports which are beyond the capacity of the informal system.

The attainment dimension relates to the amount of achievement in each domain. In general, the respondents rated the degree of attainment in the various domains slightly higher than the comparative evaluations in the satisfaction dimension. The two global questions at the end of the survey also highlighted the

relationship between attainment and satisfaction. Respondents rated their attained global FQOL (\overline{X} =2.42, SD=.918) lower than their overall satisfaction with their FQOL (\overline{X} =2.73; SD=1.13). Global single-item measures allow respondents to evaluate the concept of family quality of life intuitively and spontaneously (Youngblut & Casper, 1993) and have been used successfully in life satisfaction and QOL research (Schimmack & Oishi, 2005; Zimmerman, et al., 2006). However, there is debate in the literature regarding their use (Grubb, 2006; Loo & Kells, 1998), and they should be interpreted with caution.

The marked variation from the aforementioned pattern is found in the case of attainment of meaningful values. The attainment score for meaningful values ($\overline{X}=3.86$) surpassed even the attainment score for family relationships ($\overline{X}=3.78$). To the extent that future research finds this trend to be significant, we suggest that the domain of values is the intervening concept that explains the relationship between attainment and satisfaction. Values may determine the meaning of QOL and thus explain the disparity between the strong attainment of meaningful values and the relatively poor attainment of specific support. Belief in the basic resilience of the family unit or religious and spiritual beliefs may moderate dissatisfaction with FQOL. Future research should investigate the effect of such values as hope, gratitude and other positive emotions on FQOL.

Human services and FQOL

As already noted, the respondents indicated high importance, but relative dissatisfaction, for the domains of health, finances, career, and leisure. However, the respondents indicated even greater dissatisfaction with the support that they received from disability-related services. This type of support is essential to FQOL and was

rated very highly in terms of its importance. However, the respondents indicated that they experienced less satisfaction with formal "disability" agencies than with the other domains of FQOL.

The high importance of human services and the low degree of satisfaction with them is a recurrent finding in the literature (Bailey, Skinner, Rodriguez, Gut, & Correa, 1999; Brown, et al., 2006; Wang & Brown, 2009). Previous research in Israel has likewise found that parents tend to report low satisfaction with disability service agencies and generally encounter difficulty in obtaining needed services or in receiving services of sufficient quality or quantity (Strosberg, et al., 2000).

The attainment dimension provides another window to understanding the attitudes of these families to the agencies that serve them. Whereas satisfaction with disability services is rated relatively low, the attainment score is considerably higher and on a level with the attainment scores in the domains of community involvement and informal support. This may indicate that the dissatisfaction is not a result of the actual, concrete services received, but rather of the way in which those services are provided. Quality of Life (QOL) is a construct based on both objective and subjective criteria. Objectively, service may be relatively adequate, but the subjective quality of service and the experience of the clients while receiving the service may explain the dissatisfaction.

This interpretation of the findings is indeed disturbing insofar as it challenges the claims of many service agencies that they are "family friendly." Future research should focus on identifying specific areas of dissatisfaction with the service system so as to facilitate changes in service structure and policy that take the needs of the whole family into account. It is also important for future research to determine the extent to which the low satisfaction with disability service agencies in the Arab sector is a

result of low professional standards, bureaucratic inefficiency, or structural difficulties (geographical distance, transportation, language, etc.).

Cultural sensitivity to minorities and acceptance of religious and cultural differences are essential in a "family friendly" service. Today, the socio-political environment for minorities with intellectual disabilities and other special needs is especially challenging. Israeli Arab families with special needs find themselves in a complex system of public services, partially government funded services, private services, fraternal services, and union-affiliated services, among others. Each of these has different geographic service areas, eligibility requirements, fee structures, and sets of rules and regulations. The demands of numerous service organizations that are linguistically and culturally challenging, together with the lack of structures interfacing and coordinating between the community and the general public, may be extremely stressful for minority families with special needs.

Limitations

Several limitations of this study should be considered. First, the respondents did not constitute a random sample. Thus, the sample may differ from the developmental disability population in the Israeli Arab sector as a whole, and therefore the findings cannot be generalized beyond the present sample. Nonetheless, it should be noted that studies from other countries using similar methods with the same research instrument and with similar results show a consistency of trends and add support for our results. Even when understood in the light of similar findings from other studies, however, the lack of a randomly selected, representative sample greatly limits the strength of our findings.

Second, we asked the main caregivers of the families to inform us not about their own QOL, but about the QOL of the family as a whole. Further research should gather responses of other family members as well and investigate the extent to which one informant can serve as a proxy for the quality of life of the family as a whole. Third, our findings are based on a family "snapshot" of a moment in time, but family life is in fact dynamic, with some aspects becoming more or less central to the life of the family at different times (Neikrug, Judes, Roth, & Krauss, 2004). Fourth, challenges were encountered regarding translation of the instrument, and these must be continually evaluated for future cross-cultural research endeavors. Lastly, further research should include more in-depth reliability evaluation. This will be particularly important for utilizing the results of the FQOL to improve interventions and enhance the quality of life of clients in organizational/service settings.

Conclusion

Families with children who have disabilities are strongly challenged to meet the needs of the special child while also meeting the needs of all its members. Our findings indicate that the *Family Quality of Life Survey is* a valuable tool for gathering information on the family as a whole. It identifies areas of satisfaction and strength, as well as areas of family concern. Domains that are given low FQOL ratings provide an opportunity for service agencies to consider the family as a whole and focus on serving the pressing needs of the family.

In general, the results of this study compare well to the findings of the other countries that participated in the International Family Quality of Life Project (Brown, 2008; Wang & Brown, 2009; Werner, et al., 2009). Data presented by Brown (2008; 2012b) and Wang & Brown (2009) have also summarized findings from previous

studies in several other countries using the *Family Quality of Life Survey*. Similar to our findings, satisfaction with the domains of family, friends, and significant others was highly rated as compared to the other domains.

Israeli Arab families face unique challenges in managing the specific problems of children with disabilities. In addition to the numerous difficulties encountered by all Israeli families who have children with disabilities, those of Arab families are compounded by their status as a minority group. The domains of FQOL that depend upon the resources of the formal support network were viewed by the respondents in this study as being unsatisfactory in comparison to the other domains of their family life. Further research should investigate the policies and services of the formal support network in order to identify the barriers that interfere with the receipt of quality health services and to determine which employment policies must be changed so as to allow parents of children with disabilities to contribute to the economy to the full extent of their ability. Our instrument measures FQOL in distinct domains; yet, it is clear that these domains exist in an open system, influencing each other and being influenced by the environment. Future research should attempt to identify the pivotal domains that can have a major impact on the system as a whole.

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Table 1: Age distribution of individuals with disability

Age group	percentage
0 – 4	22 %
5 – 12	35 %
13 – 21	23%
22 +	20%

Table 2: Domains of FQOL – Means and standard deviations

Domains	Mean	SD
Family relationships	3.66	.89
Community	3.18	.71
Support from others	3.15	.92
Health	2.99	.91
Leisure	2.91	.88
Career	3.13	.83
Financial	2.81	.91
Service support	2.85	.86
Values	3.56	.73

Table 3: Dimensions of FQOL – Means and standard deviations

Dimension	Mean	SD
Attainment	2.95	.87
Stability	2.90	.77
Opportunity	2.64	.91
Initiative	3.16	.85
Importance	4.37	.74
Satisfaction	2.82	.98

Table 4: Means and standard deviations of the importance of FQOL domains

Domains & Dimension of Importance	Mean	SD
Family relationships	4.54	.67
Community	3.83	.82
Support from others	3.7	1.07
Health	4.6	.76
Financial	4.76	.49
Leisure	4.72	.51
Career	4.36	.63
Service support	4.43	1.0
Values	4.41	.62

Table 5: Means and standard deviations of satisfaction with FQOL domains

Domains & Dimension of	Mean	SD
Satisfaction		
Family relationships	3.71	1.06
Community	3.31	.89
Support from others	3.2	1.06
Health	2.57	1.10
Leisure	2.20	.963
Career	2.60	1.021
Financial	2.16	.998
Service support	2.02	.850
Values	3.60	.888

Table 6: Means and standard deviations of attainment of FQOL domains

Domains & Dimension of Attainment	Mean	SD
Family relationships	3.78	.83
Community	2.98	.71
Support from others	2.92	.97
Health	3.23	.84
Financial	2.58	1.20
Leisure	2.37	1.00
Career	2.80	.90
Service support	2.92	.97
Values	3.86	.626