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A NEW WAY TO VIEW PERCEPTIONS OF THE QUALITY OF LIFE OF FAMILIES WHO HAVE A CHILD WITH TOURETTE SYNDROME

ABSTRACT. Khoury Rita, *A New Way to View Perceptions of the Quality of Life of Families Who Have a Child With Tourette Syndrome* [Nowe spojrzenie na jakość życia rodziny dziecka z syndromem Tourette'a]. *Studia Edukacyjne* nr 36, 2015, Poznań 2015, pp. 425-442. Adam Mickiewicz University Press. ISBN 978-83-232-2958-2. ISSN 1233-6688. DOI: 10.14746/se.2015.36.24

The purpose of this study was to gather data from the families of children with Tourette Syndrome (TS), in order to examine the extent to which the existence of a child with TS in the family affected their Family Quality of Life (FQOL). The research was conducted according to the mixed methods approach, combining quantitative and qualitative methods. Data was collected from 25 families of children with TS. The questionnaire was analyzed statistically and the interviews were analyzed using a content analysis method. Conclusions derived from the research findings allowed the development of the ACEIST model, including five new sub-domains of FQOL that reflect the experiences of the studied families: advocacy, cooperation, explanation, information, and the severity of TS. This is a new way to view the FQOL of families who have a child with TS which is very precise, functional and family-specific. This ACEIST model fills the knowledge gap in this field, contributing to our knowledge regarding the FQOL of families who have a child with TS. The new model has practical implications for education as well as social and health policies in Israel regarding families who have a child with TS.

Key words: perceptions, families, quality of life, Tourette Syndrome

Tourette Syndrome is a neuropsychiatric disorder named after Dr. Georges Gilles de la Tourette (1857-1904). It is an inherited, neurological disorder characterized by repeated involuntary movements and uncontrollable vocal (phonic) sounds called tics. In some cases, such tics can include inappropriate words and phrases.¹ The symptoms of TS generally appear before

¹ N. Dreher, *What is Tourette Syndrome?* *Current Health*, 1997, 23, p. 21.

the individual is 18 years old and usually at the age of six to seven years old.² TS can affect people of all ethnic groups, and it appears to be familial (i.e. it 'runs' in families). Recent information appears to indicate that there is likely to be a significant genetic factor responsible for its genesis. Research by Abelson et al.³ reviewed some of the genetic research and identified a new candidate gene. Gender is also linked to the incidence of TS: boys are significantly more likely to develop TS than girls; males are affected three to four times more than females.⁴

Most people with TS experience additional problems such as Obsessive Compulsive Disorder (OCD).⁵ Additional problems may include Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)⁶; learning disabilities (LD), which include reading, writing, arithmetic, and perceptual difficulties; problems with impulse control, which can result in overly aggressive behavior and socially inappropriate acts; or sleep disorders, which include frequent awakenings or talking in one's sleep.⁷

Having a child with Tourette Syndrome (TS) seriously challenges parents who aspire to raise a 'normal' family, because of the stresses and strains engendered by the unusual behavior of the child with TS.⁸ As mentioned above, children with TS may experience a wide range of psychological, behavioral and psychiatric problems in addition to vocal and motor tics. These difficulties also lead to interpersonal communication problems, feelings of anxiety and mood-changes, and may be accompanied by difficulty in concentrating, hyperactivity and obsessive behaviors⁹. These children usually find it hard to adapt their behavior to their environment and their particular characteristics may have a negative impact on the child's functioning at school. In addition to their difficulties in daily functioning in school, children with TS exhibit significant problems with labile emotions, impulsivity,

² J. Swain et al., *Tourette Syndrome and tic disorders: A decade of progress*, Journal of the American Academy of Child & Adolescent Psychiatry, 2007, 46(8), p. 947-968.

³ J.F. Abelson et al., *Sequence variants in *slitrk1* are associated with Tourette's Syndrome*, Science, 2005, 310(5746), p. 317-320.

⁴ N. Dreher, *What is Tourette Syndrome?* p.21

⁵ M. Robertson, S. Baron-Cohen, *Tourette Syndrome: The facts*, Oxford 1995.

⁶ M.M. Robertson, *Tourette Syndrome, associated conditions and the complexity of treatment*, Brain, 2002, 123, p. 425-462.

⁷ R.L. Albin, J.W. Mink, *Recent advances in TS research*, Trends Neurosci, 2006, 293, p. 175-182.

⁸ R.W. Greene, *The explosive child: A new approach for understanding and parenting easily frustrated chronically inflexible children*, New York 1996/1997, p. 11361-2820.

⁹ D.A. Carter et al., *Social and emotional adjustment in children affected with Gilles de la TS's syndrome: Associations with ADHD and family functioning*, Journal of Child Psychology and Psychiatry and Allied Disciplines, 2000, 41, p. 215-223.

and aggression directed at others¹⁰. Usually, this situation engenders confusion, helplessness and sometimes an inability to maintain 'normal' family life. Instead of turning to counseling or seeking help, some families withdraw within themselves¹¹.

Research conducted among families of children with disabilities found that most of the families who have children with disabilities receive no help in dealing with their child¹². Thus, raising a child with TS has significant implications for the family's everyday life. Like other families who deal with a child with a disability, families of children with TS also undergo crises and changes in various areas of family life. Those changes may appear in the family when viewed as an organization and a system, changes in systems of relations between parents and children and also within the parental relationship. There have been few studies specific to families of children with TS in Israel. However, it has been found that the birth of a child with TS in some cases creates a crisis situation for the family, which has many implications for the family's lifestyle.¹³ Many studies indicate that the family is an important mediating factor in the emotional and social adjustment of the child. For this reason, information regarding the manner in which parents and siblings of children with TS tend to respond to this crisis situation and their coping strategies can help professionals in the mental health field, as well as the doctors and neurologists who may encounter such families in the future. It can also help the families themselves to better understand how the birth of a child with TS affects the family, and help them learn better ways of dealing with the many difficulties that arise while raising a child with TS together with their other children in the family. The next section discusses conceptions of FQOL in relation to families who have a child with TS.

As noted above, researchers have for many years studied the QOL of individuals within the family, and have only recently begun to pay attention to the issue of FQOL.¹⁴ Therefore, the definition of the concept of FQOL relies on many definitions developed with regard to individual QOL.

¹⁰ J. Piacentini et al., *Functional impairment in children and adolescents with obsessive-compulsive disorder*, *Journal of Child and Adolescent Psychopharmacology*, 2003, 13, Supplement 1, p. 61-69.

¹¹ Tourette Syndrome Organisation, Israel, TSOI, 2008.

¹² A.P. Turnbull, "Wearing two hats": *Morphed perspectives on family quality of life*, *Mental Retardation*, 2004, 42(5), p. 383-399.

¹³ R. Levy-Shiff, *International and domestic adoption: Child, parents, and family adjustment*, *International Journal of Behavioural Development*, 1997, 20(1), p. 109-129; R. Levy-Shiff et al., *Cognitive appraisals, coping strategies, and support resources during transition to parenthood as correlates of parenting and infant development*, *Developmental Psychology*, 1998, 34, p. 1417-1427.

¹⁴ A.P. Turnbull, V. Turbiville, H.R. Turnbull, *Evolution of family-professional partnership models: collective empowerment as the model for early 21st century*, [in:] *The handbook of early child-*

Any discussion of QOL usually refers to how 'good' life is. If human beings are seen as organisms with 'potential', capable of mental and social self-realization, then the purpose of life is the ability to allow this 'potential' to develop in both an individual and ecological context. Therefore, QOL, or in other words, 'a good life', means the ability to maximize life's 'potential' in a particular social and ecological context.

QOL is shaped by a variety of life conditions that interact in complex ways. What is considered to be a 'good' life is different for different people. People in various parts of the world have defined quality in their lives in rather distinct ways. Different groups and individuals often think of QOL in ways that are specific to their own life situations and their own characteristics. But a slightly more profound examination of this issue reveals that it is not always a simple task to determine how 'good' life is or what the meaning or purpose of life is. QOL relates to the person's general expectations of life, therefore, its conceptualization varies according to individual perceptions.¹⁵

In many cases, QOL relates to a cognitive judgment regarding satisfaction with life and an affective assessment of emotions and moods. It relates to individuals' overall assessment of their internal experiences, including thoughts, attitudes, motives, dreams, and emotions¹⁶, and their subjective and intuitive assessment of the quality of their experience as they are able to rationally and responsibly report. QOL may not be explainable solely on the basis of objective situations that the individual experiences, as it is affected by the individual's personal perceptions and attitudes¹⁷, and therefore, different people will not necessarily assess the same life circumstances in the same way.

From a historical perspective, the definitions of QOL have changed over the last decades, and the term has been defined differently by different researchers. Thus, QOL has been defined as the difference between the hopes

hood intervention, Eds J.P. Shonoff, S.L. Meisels, 2nd ed., New York 2000, p. 630-650; B.G. Isaacs et al., *The International FQOL Project: Goals and description of a survey tool*, Journal of Policy and Practice in Intellectual Disabilities, 2007, 4(3), p. 177-185; A.F. Burgess, S.E. Gutstein, 'Quality of life for people with autism: Raising the standard for evaluating successful outcomes', Child and Adolescent Mental Health, 2007, 12, p. 2; C.W. Jackson et al., *FQOL following early identification of deafness, Language, Speech, and Hearing Services in Schools*, Online 2009.

¹⁵ I. Brown et al., *FQOL: Canadian results from an international study*, Journal of Developmental and Physical Disabilities, 2003, 153, p. 209-230.

¹⁶ E. Diener, R.E. Lucas, *Personality and subjective wellbeing*, [in:] *Hedonic Psychology: Scientific Perspectives on Enjoyment, Suffering and Well-Being*, Eds D. Kahneman, E. Diener, N. Schearz, New York 1997.

¹⁷ W. Pavot, E. Diener, *Review of the satisfaction with life*, Psychological Assessment, 1993, 5(2), p. 164-172.

and expectations of the individual and their present experience¹⁸, while others see QOL as a sense of personal satisfaction that is more than contentment and happiness but less than fulfillment¹⁹. It is experienced when a person's basic needs are met and when he or she has the opportunity to pursue and achieve goals in definitive life settings, namely, work, school, home, and community²⁰.

Although QOL is defined in different ways, researchers have agreed on two fundamental concepts: QOL is multi-dimensional, and it includes both subjective and objective dimensions²¹. Thus, in QOL research, a distinction is often made between subjective and objective QOL²². Subjective QOL is about feeling good and being satisfied with things in general. Objective QOL is about fulfilling the societal and cultural demands for material wealth, social status and physical well-being.

QOL is also the degree to which people enjoy the important possibilities in their lives²³. Possibilities result from the opportunities and limitations that people are offered in their lives and reflect the interaction of personal and environmental factors. QOL includes, but is not limited to, the social, physical and emotional functioning of the child and the adolescent, and when indicated, the family members, and it necessarily alters according to changes that occur throughout the child's development. QOL is measured by the difference, at a particular period of time, between the hopes and expectations of the individual and the individual's present experience. It is influenced by the individual's past experience, present lifestyle and personal hopes and ambitions for the future²⁴.

As mentioned earlier, this research seeks to explore the perceived FQOL of families who have a child with TS, with the hope that this exploration and the insights gained from this process might inform best practice and assist policy makers who treat and determine policy for these families. FQOL is

¹⁸ K.C. Calman, *Quality of life in cancer patients: An hypothesis*, Journal of Medical Ethics, 1984, 10, p. 124-127.

¹⁹ D.L. Coulter, *Home is the place: Quality of life for young children with developmental disabilities*, [in:] *Quality of Life: Perspectives & Issues*, Ed. R.L. Schalock, Washington DC 1990, p. 61-69.

²⁰ D.A. Goode, *Quality of life for persons with disability: A review and synthesis of the literature*, The Valhalla NY 1988.

²¹ A.S. Halpern, *Quality of life and conceptual framework for evaluating transition outcomes*, Exceptional Children, 1993, 596, p. 486-498.

²² Quality-of-Life Research Unit, Toronto 2001.

²³ H. Ouellette-Kuntz, B. McCreary, *Quality of life assessment for persons with severe developmental disabilities*, [in:] *Quality of life in health promotion and rehabilitation*, Eds R. Renwick, I. Brown, M. Nagler, Thousand Oaks CA 1996, p. 268-278.

²⁴ K.C. Calman, *Quality of life in cancer patients: An hypothesis*, Journal of Medical Ethics, 1984, 10, p.124-127.

defined as 'a dynamic sense of wellbeing of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact'.²⁵

With cautious inference from the descriptions and principles used in the literature for the measurement of individual QOL, FQOL measures the degree to which families have meaningful life experiences that they value. FQOL measurement can serve as an impetus to guide families to move toward a meaningful life that they can enjoy and value, and measures the degree to which life's domains contribute to a full and interconnected life. FQOL measurement is undertaken within the context of environments that are important to families: where they live, work and play. It is important to mention that FQOL measurement is based upon both common human experiences and unique, individual family experiences.

There has been increased interest in research on the topic of families, and how they are affected by the presence of a child with a disability within the family²⁶, but the issue of FQOL has not been studied until quite recently. Researchers found that the presence of a child with a disability in the family affects interpersonal relations within the family²⁷. It is well known that when relations are fulfilling, everything functions well, and this affects both the QOL of the individual within the family, and the family as a unit. Similarly, when one family member has a certain disability, and relations are undermined or tension is caused in the family, this may negatively affect both the individual within the family and the family unit²⁸. It follows, then, that the existence of a child with TS in the home might affect the family members' perception of the FQOL. This section has discussed how FQOL is perceived by the research literature. The next section delineates in more detail the domains that comprise FQOL.

Five main domains of FQOL were identified, based on extensive qualitative²⁹ and quantitative³⁰ analyses. These findings formed the basis of a pilot

²⁵ N.I. Zuna, *Confirmatory factor analysis of a family quality of life scale for families of kindergarten children without disabilities*, *Journal of Early Intervention*, 2009, 31(2), p. 111-125.

²⁶ C. Baxter, R.A. Cummins, L. Yiolitis, *Parental stress attributed to family members with and without disability: A longitudinal study*, *Journal of Intellectual & Developmental Disability*, 2000, 25, p. 105-118.

²⁷ R.A. Cummins, C. Baxter, *The influence of disability and service delivery on quality of life within families*, *International Journal of Practical Approaches to Disability*, 1997, 213, p. 2-8.

²⁸ L.M. Glidden et al., *Family functioning when rearing children with developmental disabilities*, [in:] *Cognitive coping, families, and disability*, Eds A.P. Turnbull, J.M. Patterson, S.K. Behr, D.L. Murphy, J.G. Marquis, M.J. Blue-Banning, Paul H. Brookes, Baltimore 1992, p. 183-194.

²⁹ D. Poston et al., *FQOL outcomes: A qualitative inquiry launching a long-term research programme*, *Mental Retardation*, 2003, 41(5), p. 313-328.

version of the Beach Centre FQOL Scale³¹. Park conducted initial development and psychometric evaluation of the pilot FQOL scale. After further evaluation of the factor structure of the scale, they identified five uni-dimensional FQOL domains: Family Interaction, Parenting, Emotional Well-being, Physical and Material Well-Being and Disability-Related Supports. The FQOL scale measures family members' perceptions of the importance of those domains and their level of satisfaction regarding the domains.

There is a growing understanding among disability researchers that disability is socially constructed, meaning that it is defined variably across cultures³². Culture is defined as '*everything that people have, think and do as members of society*'³³. Culture influences the way in which families define and experience disability. Cultural differences and parental perceptions are considered key factors in interactions between parents and professionals. Research and practice regarding child development reveal how important it is to understand the family's context and to recognize the family's cultural backgrounds.

Socio-cultural influences on the parents' perceptions of their child with a disability are recognized within an ecological model³⁴, a transactional model³⁵, and relationship-based approaches³⁶. These models consider the child as a point of focus within the immediate context of his/her family, community, and social services. These models also view the family, and its cultural background, as having a critical role in the development of children with disabilities³⁷. Within this socio-cultural context and the daily difficulty

³⁰ I. Brown et al., *FQOL: Canadian results from an international study*, *Journal of Developmental and Physical Disabilities*, 2003, 153, p. 209-230; L. Hoffman et al., *Assessing family outcomes: Psychometric evaluation of the Beach Center FQOL Scale*, *Journal of Marriage and Family*, 2006, 68(4), p. 1069-1083.

³¹ J. Park et al., *Toward assessing family outcomes of service delivery: Validation of a FQOL survey*, *Journal of Intellectual Disability Research*, 2003, 474(5), p. 367-384.

³² R. Olkin, *What psychotherapists should know about disability*, New York 1999; P.M. Ferguson, *Disability studies and the exploration of parental response to disability*, [in:] *Handbook of Disability Studies*, Eds G.L. Albrecht, K.D. Seelman, M. Bury, Thousand Oaks CA 2001, p. 373-395.

³³ G. Ferraro, *Cultural anthropology*. St. Paul MN 1995.

³⁴ Bronfenbrenner, *The ecology of human development: Experiments by nature and design*, Cambridge MA 1979

³⁵ A.J. Sameroff, B.H. Fiese, *Transactional regulation: The developmental ecology of Early Intervention*, [in:] *Handbook of early childhood intervention*, Eds J.P. Shonkoff, S.J. Meisels, Cambridge UK 2000, p. 135-159.

³⁶ J. Bertacchi, *Relationship-based organizations*, *Zero to Three*, 1996, 17, p. 1-7; C.G. Goetz et al., *Advantages of a modified scoring method for the Rush Video-Based Tic Rating Scale*, *Movement Disorders*, 1999, 14, p. 502-506.

³⁷ S.A. Burnett, P.A. Meares, *Infants and toddlers with disabilities: Relationship-based approaches*, *Social Work*, 2000, 45, p. 371-380.

involved in containing the child with TS at home, in the educational framework, and in various social frameworks, this research examined how families with children who have TS, in a variety of cultural contexts, perceive their family quality of life.

The questions that guided the research were: 1. Which FQOL domains are perceived by family members to be affected by the fact that they have a child with TS?

2. How do different families raising a child with TS perceive their FQOL?

The conceptual framework of this research

Systems Theory and the *Ecological Model* were selected to explain how the family with a child with TS operates and functions as a system. Systems Theory was the name used by early investigators to describe the organization and interdependence of relationships³⁸, and was defined as a set of objects or elements in interaction to achieve a specific goal³⁹. Systems theory considers the way relationships within the family and between the family and the social environment influence individual development and family functioning, and provides guiding principles for family systems⁴⁰. Thus, Systems Theory explains how family members interact and what personal and interpersonal processes occur inside the family.

The Ecological Model views human development from a person-in-environment context, and emphasizes the reciprocal connections between the person and the environment⁴¹. Thus, the ecological model delineates how family members interact with the environment outside the family. Use of the two theories (Systems Theory and the Ecological Model) enables a holistic depiction of the family functioning inside and outside the family system. Figure 2 below presents a visual representation of the conceptual framework of this research.

³⁸ R. Rapoport, R.N. Rapoport, *The dual career family: A variant pattern and social change*, Human Relations, 1969, 22(1), p. 3-30.

³⁹ S.D. Ryan, M.S. Gates, *Inclusion of social subsystem issues in IT investment decisions: An empirical assessment*, Information Resources Management Journal, 2004, 17(1), p. 1-18.

⁴⁰ M. Bowen, *Family therapy in clinical practice*, Jason Aronson Inc., Northvale NJ 1978.

⁴¹ K. Kreppner, R. Lerner, *Family systems and the life span development: Issues and perspectives*, [in:] *Family systems and life-span development*, Eds K. Kreppner, R. Lerner, New Jersey 1989.

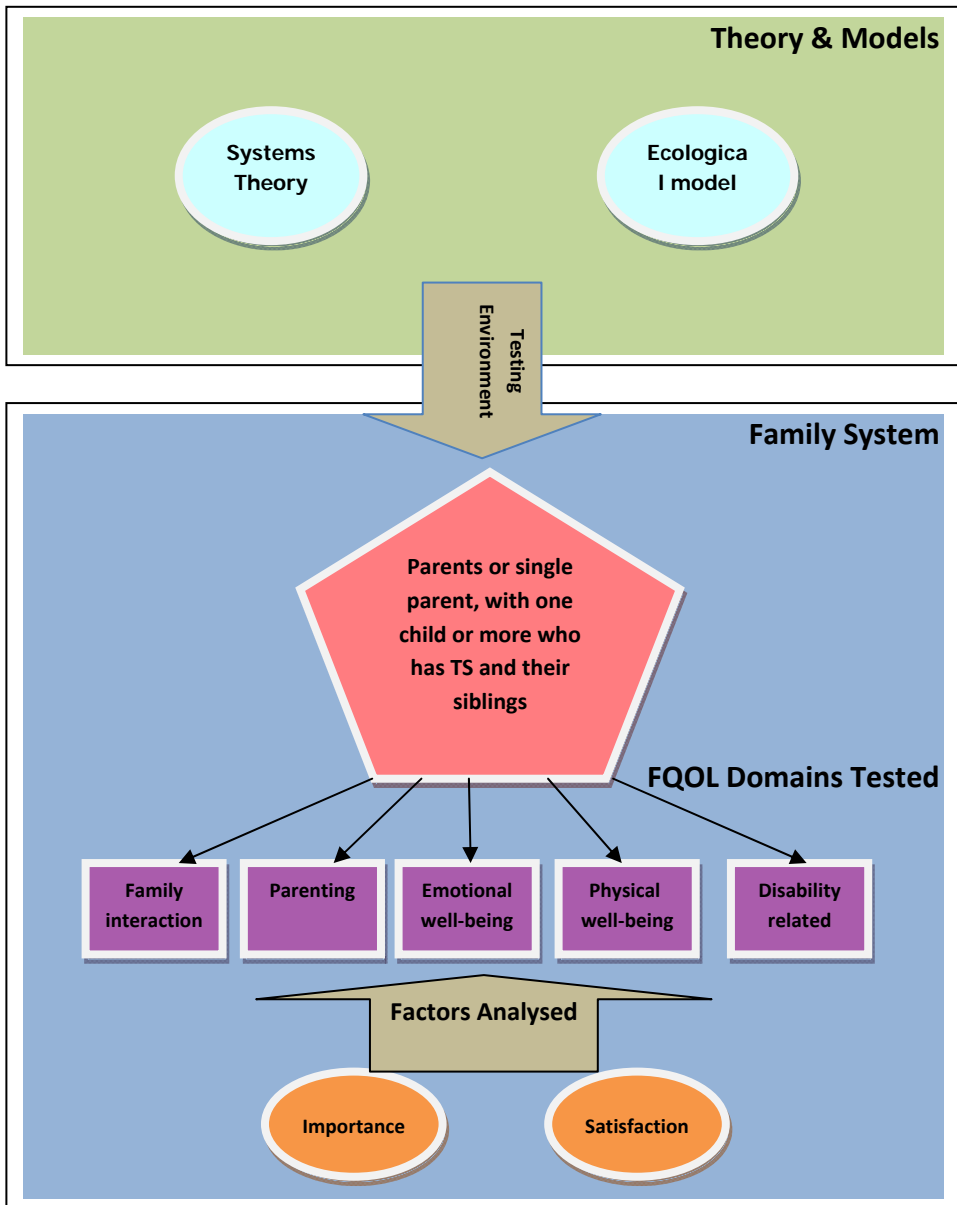


Fig. 1. Representation of the Interactive Process between the Ecological Model and Systems Theory

The Figure above shows the interaction between the components that were involved in the research process and the way that they complement

each other. Systems Theory and the Ecological Model are used in this research to explain FQOL. The family system is composed of parents or a single parent, siblings and the child with TS. The family perceptions of the importance of the different domains of FQOL and their levels of satisfaction in these domains are the indicators of their FQOL. According to the model, the family system is located in the centre of the model, in order to demonstrate the centrality of the family unit and the ways in which Systems Theory and the Ecological Model explain the dynamics inside and outside the family that has a child with TS. Thus, the child with TS as part of the family affects the type of parenting and the relationships among the siblings. Similarly, the child with TS affects the dynamics between the family and the environment outside the family unit. The dynamics inside and outside the family unit generate the FQOL as an outcome.

Ultimately, the research advanced an understanding of the perceived FQOL of families who have a child with TS within the Israeli context. This was presented in the research as something which could have implications for better treatment practice and better training of treatment providers in this field.

Methodology

Since the research sought to examine the FQOL of families who have a child with TS, and with no pre-determined hypotheses available, an inductive research design approach was adopted⁴². A mixed-methods research strategy was implemented to provide a holistic view of this phenomenon⁴³. The research was conducted in two stages. Stage 1 applied a quantitative approach, employing a closed-ended questionnaire to measure the extent to which families with a child with TS were satisfied with their FQOL in the five FQOL domains. In Stage 2, a qualitative approach⁴⁴ was used to address related issues and deepen the understanding of the families' perceptions of their FQOL. Interviews⁴⁵ were conducted with the families to ascertain their views, opinions, and feelings. Statistical analysis⁴⁶ was employed to assess

⁴² J.W. Creswell, *Research design: Qualitative, quantitative, and mixed methods approaches*, 2nd ed., Sage Publications, London 2003.

⁴³ L.A. Curry, I.M. Nembhard, E.H. Bradley, *Qualitative and mixed methods provide unique contributions to outcomes research*, *Circulation*, 2009, March 17, 119(10), p. 1442-1452.

⁴⁴ D. Ortiz, J. Greene, *Research Design: Qualitative, Quantitative and Mixed Methods Approaches Book Review on line*, *Qualitative Research Journal*, 2007, 6(2), p. 205-207.

⁴⁵ A. Oppenheim, *Questionnaire design, interviewing and attitude measurement*, Pinter, London 1992.

⁴⁶ K.R. Murphy, B. Mayers, *Statistical power analysis: A simple and general model for traditional and modern hypothesis tests*, Mahwa NJ 1998.

the data collected through the closed-ended questionnaire, while content analysis⁴⁷ was employed to analyze the opinions and views expressed in the interviews.

The research population, families of children with TS over the age of seven, were chosen for this research for a number of reasons. Several studies indicate⁴⁸ that families of children with TS begin experiencing difficulties after the child reaches age six-seven because it is only at this age that the verbal and motor tics begin to appear and TS is usually not diagnosed until this age⁴⁹. As children begin schooling in Israel at the age of six/seven, until this time, families are generally not aware of the full implications of the child's TS. The family may go through a sudden change, with unclear ramifications regarding the family's future functioning, which entails feelings of frustration, helplessness and fear.

Findings

The research indicated that the main need of these families is to receive truthful, accurate and comprehensive **information** from professionals concerning the nature of TS and its implications. Accurate information about the syndrome at the early stages of diagnosis can apparently prevent parents from acting inappropriately or even violently towards their children with TS in order to 'discipline' them, and allow better understanding of the child's situation. Parents blamed themselves for many years for their violent behavior towards their children with TS, and felt that they were 'not good' parents. However, when parents received accurate information about the syndrome, it helped them to organize their priorities correctly, and understand that what was really important was to provide the help that the child with TS needs. Additionally, having accurate information apparently helped the parents to stand up more forcefully to their extended family and friends when they needed to deal with prejudices regarding their child with TS. If explanations did not help and grandparents and aunts and uncles did not change their attitude concerning the behavior of the child with TS, the parents at least felt more comfortable after they knew the facts about the syn-

⁴⁷ K. Carley, *Content analysis*, [in:] *The Encyclopedia of Language and Linguistics*, Ed. R.E. Asher, Edinburgh 1990.

⁴⁸ M.M. Robertson, *Tourette Syndrome, associated conditions and the complexity of treatment*, *Brain*, 2002, 123, p. 425-462.

⁴⁹ M.M. Robertson, M.R. Trimble, A.J. Lees, *The Psychopathology of the Gilles de la Tourette Syndrome*, *British Journal of Psychiatry*, 1988, 152, p. 383-390.

drome and what should be done to help the child, even if it meant distancing themselves from extended family and friends.

Once they had accurate information about the syndrome, most parents seemed able to maintain a balance in the family and could provide **explanation** and support to the other children. Parents felt that they would also be able to plan their child's treatment at the early stages of the emergence of the symptoms if they had the proper information.

Knowledge of the symptoms of the syndrome at an earlier stage could guide the parents' reactions towards their children, and if this were successful they would be able to perceive themselves as successful parents, and this would help them serve as a better and more positive example to their other children.

As it was, the parents often lacked sufficient information and support, and it was found that parents felt that they neglected their other children and were unable to fix this. They were often not sensitive enough towards the other siblings, and did not share their emotions or information with them. When they were given accurate information, they seemed to be more able to explain the syndrome to their other children and thus prevent misunderstandings, and consequent unpleasant situations and confusion among their children in all areas relating to the syndrome. Siblings did not have to speculate regarding the nature of the problem their brother or sister had. They did not feel so ashamed when facing their friends, and they did not unnecessarily fear that the difficulties of their sibling with TS indicated that the child was going to die. Transmission of accurate information to siblings opens channels for family communication and **cooperation** and thus decreases unnecessary stress.

It appeared that all families benefitted from coordination which enabled them to maintain a 'normal' life. However, when it comes to families who have a child with TS, **cooperation** between the parents seems to be critical. A child with TS needs much attention, as well as medical and psychiatric treatment. Most of the time, he or she needs to be accompanied at school and outside the house. Parents of children with TS face many challenges in raising a child with TS. Therefore, **cooperation** between them could decrease stress and tension, employing open conversations that could prevent feelings of isolation. Cooperation between the parents meant that there was an effective division of roles between them and that the burden did not fall only on one of the parents. Such a relationship apparently sustained parents and enabled them to deal with the day-to-day stresses, providing tools to decrease tension. It seems that when there is adequate cooperation, parents do

not feel so exhausted and have more time and energy to give attention to the other children in the family, and siblings do not feel neglected.

In addition, it seems to be essential for parents to have accurate information about the syndrome so that they can act as **advocates** for their children when facing teachers and other professionals who work in the educational system and have relations with their child with TS. In order that these professionals can help the child with TS to integrate and function within the education system, they need to be sensitive to the difficulties of the child and those of the parents. The findings of the present research show that in most cases the professional functionaries of the education system give up and send the child with TS home, leaving him or her without any educational solution. When advocating for their child with TS, it appears that the parents must be equipped with relevant knowledge so that professionals and decision makers in the educational system can also understand the problem better and be more willing to deal with the difficulties. In this case, it would be easier if the professional bodies involved could see the child with TS as a child who needs emotional, behavioral and sometimes academic support.

The **Severity** of the TS seems to constitute a variable that amplifies the level of difficulty of each of the newly identified sub-domains. Thus, for example, as shown previously, if the severity of the TS is greater, there will be a greater need for **Advocacy**, in order to maintain the FQOL of families who have a child with TS. In addition, **Services** for the family and for the child with TS seem to be the most significant domains of FQOL for families who have children with TS, in particular services provided by the educational and medical systems.

The educational framework was found to be the most influential variable affecting FQOL for families of children with TS. Parents expressed their dissatisfaction with the educational framework, but also expressed hope that if the educational system could learn to deal with the child with TS, then there would be an improvement in their QOL.

Conclusions

The research advances the ACEIST model as a new way to view the FQOL of families who have a child with TS, providing new understanding concerning the components of their FQOL.

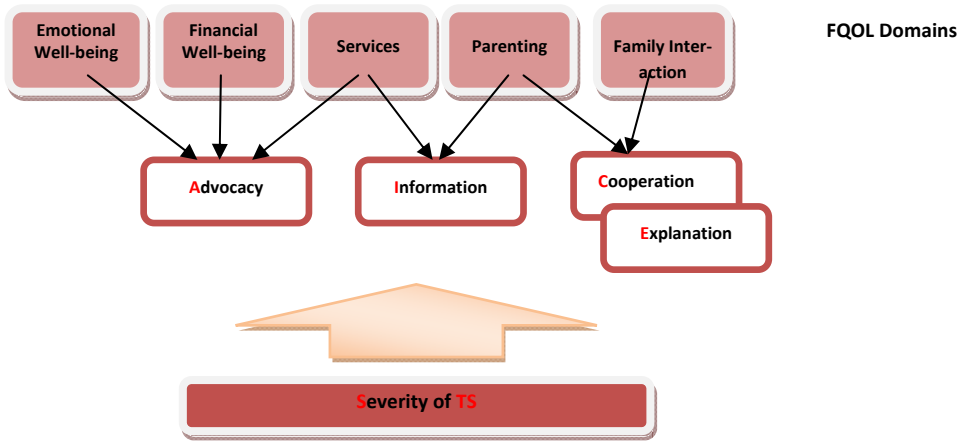


Fig. 2. The ACEIST Model: New FQOL Sub-domains involved in the FQOL of Families who have a Child with TS

This model presents an accurate and applicable approach to this issue that can be employed as a tool in order to assess and examine the FQOL of these families through research. The ACEIST model includes five sub-domains of FQOL, Advocacy, Cooperation, Explanation, Information Services and Severity of TS. '**Advocacy**' emerged in both the 'emotional well-being' and 'services for the child and family' domains of FQOL. This sub-domain relates to the need to advocate for the child with TS in its relations with society. In particular, it relates to the need to explain to and influence educational professionals, extended family, and friends in order to provide the best possible care and protection for the child with TS. '**Cooperation**' emerged in both the QOL domains: 'family interaction' and 'parenting'. Cooperation relates to the ability of the parents to cooperate in order to fulfill their parenting role by creating a warm and positive atmosphere in the home and by preventing feelings of tension and stress, and siblings' feelings of neglect and isolation. '**Information**' emerged in both the QOL domains: 'parenting' and 'services for the child and family'. This sub-domain relates to the parents' need to obtain truthful and correct information from doctors and counselors who know and understand the disorder. It seems that accurate information could prevent inappropriate behavior toward the child with TS and his or her siblings, and assuage parents' feelings of guilt so that they could act and perceive themselves as good parents. '**Explanation**' emerged in both QOL domains: 'Family interaction' and 'Parenting'. 'Explanation' relates to the process in which parents struggle to explain the phenomenon of

TS to their other children. According to the research findings, 'The **Severity of the TS**' seems to constitute a variable that amplifies the level of difficulty of each of the newly identified sub-domains. Thus, for example, as shown previously, if the severity of the TS is greater, there will be a greater need for Advocacy, in order to maintain the FQOL of families who have a child with TS.

This model presents an accurate and applicable approach to this issue that can be employed as a tool in order to assess and examine the FQOL of these families through research.

Recommendations

The conclusions that emerged from this study seem to allow the advancement of several recommendations that can serve as a framework OR model to help families, educators and therapists cope more effectively with the difficulties of a child with TS. Lack of accurate diagnosis and information may lead families to a state of imbalance and great stress. Professionals should understand that their role is very critical to these families. Inaccurate diagnoses or the lack of any diagnosis at all leaves families with a feeling of helplessness when dealing with the misunderstood behavior of their child with TS. The result is a state of stress that permeates to each family member, and thus negatively impacts the family as a unit.

Additionally, the educational framework seems to avoid and reject any attempt to understand the important role it plays in the lives of these families. In the Israeli reality, children with TS are not defined as children with special needs. This research indicates that children diagnosed as having TS need to be included within this special group in order to receive appropriate educational and therapeutic assistance. Inclusion within this definition would help to improve the FQOL of those children's families. This research offers this knowledge as a recommendation for government education policy in Israel.

The results that emerged from this research also have implications for the policy of the Ministry of Health. It is recommended that family doctors and pediatricians receive training to raise their awareness and knowledge regarding children with TS in order to avoid parents' exhausting searches for accurate diagnoses and advice and medical treatment with the consequent saving of the family's financial resources. Evidently, the need to constantly supervise the child with TS in order to prevent unsafe behavior meant that parents often neglected the child's siblings. Families ceased their activities outside the home because they did not want to hear the comments

of neighbors and friends. It is recommended that awareness towards TS should be raised amongst the community through the social services in order to avoid ignorance regarding this syndrome. Advocacy should not be the exclusive realm of the parents, but should also be employed by professionals, who can explain the syndrome and assist the education system in its work with children with TS.

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