

# **Quality of Life for Single Mothers With a Child Diagnosed with Autism**

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## **Introduction to the Phenomenon**

Healthcare workers need to understand quality of life for clients/persons. It is particularly significant in the vulnerable population of autistic children and their caregivers. Children are being stolen from their loved ones by autism at a rate of one in every 30 minutes (World Health Organization, 2007) yet some in society pretend it does not happen or that it is not the largest epidemic facing North America. Imagine how that translates to the caregiver of that child whose autism does not rank as an important health factor and does not merit priority research? Imagine as a parent you are told that your child will never speak, never read, and never write. Imagine hearing that your child will have social problems throughout life as the health professional bids you farewell and good luck. Would we do this to children with acute or chronic illnesses? Yet this is what parents face with a new diagnosis of autism. What is it like to hear such news and to be dismissed by those who are supposed to help?

Autism is an illness that is debilitating for the child and especially for the caregiver of the child. Days are filled with very structured routines and hours spent with what most parents accomplish with their children in seconds; mental anguish and constant monitoring of the child are ever present (Boushey, 2001). A diagnosis of autism changes one's entire world, as a parent knows it in an instant, particularly for a single mother. It is estimated that in Ontario there are 700,000 children diagnosed with Autism (Statistics Canada, 2006) and statistics have shown that marriages end 72% of the time where an autistic child is present and this rate increases to 84% when there is more than one Autistic child involved (Statistics, Canada 2006). Of these single mothers the phenomenon of their quality of life has not yet been explored. The drive for this study is that the author believes that there is a need to better understand how single mothers with a child diagnosed with autism experience their lives.

In the literature there are diverse views of quality of life studies. Specifically, many view of quality of life have been conceptualized (Gill & Feinstein, 1994; Carr & Higginson, 2001). However Carr & Higginson (2001) do agree that the persons living

with a particular illness should be considered the authorities on how it influences their quality of life. There is no known research, to the author, about single mothers with a child diagnosed with autism that studies their quality of life.

What meaning do these parents give to life and the quality of life? As nursing professionals do we consider and understand quality of life issues for family members of autistic children? Do we make assumptions or offer clichés like, “it must be difficult” without truly knowing and exploring experiences that parent’s express? This research proposal hopes to fill this gap in understanding quality of life for single mothers with a child diagnosed with autism.

The human becoming school of thought (Parse, 1981, 1992, 1997, 1998) is the theoretical perspective guiding this study on quality of life for single mothers with a child diagnosed with autism. Persons themselves define quality of life. It is simply the way life is unfolding with all the joys, sorrows, and ups and downs that shape day-to-day life. It is the meaning one gives to life situations and it involves the way people live their value priorities. It is the meaning given to a situation, as speaking being silent and moving being still discloses and at once hides the opportunities and restrictions of cherished acknowledgements. Quality of life surfaces with the certainty-uncertainty of experiencing awe filled regard, as the conforming not conforming familiar shifts with the unfamiliar in the pushing resisting of attentive reverence. From the human becoming perspective only the person’s own description discloses his or her quality of life. Only the person, who is experiencing the situation or phenomenon of interest, can describe its quality (Parse, 1994).

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