# Quality of Life in Caregivers of Children with ASD

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## Introduction

This chapter will describe (1) the ecological system within which caregivers of individuals with autism spectrum disorders (ASD) work to provide optimal care; (2) the ways in which this system may be burdened, resulting in challenges to caregiver quality of life (QoL); and (3) the strategies employed by caregivers to moderate these factors. Caregivers experience a range of issues specific to the needs and demands of caring for an individual with ASD that may impact their QoL. Caregivers may experience positive effects of the caregiving process, including the relationship with the child, personal growth, and resilience. As caregivers meet, adapt, and overcome the challenges presented to them, they may experience a positive effect on their sense of self. Not only does adaptation benefit the caregiver, being able to overcome circumstances can be beneficial for the person for whom they provide care. However, the complexity and variability of ASD may also leave caregivers vulnerable to impairments in QoL, including physical and psychological effects. Research evidence indicates that while caregivers experience multiple threats to QoL, they also use multiple coping strategies to mediate stressors associated with caring for a person with an ASD.

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This chapter will also use the ecological system theory to frame the caregivers' experience and will describe the effect of environmental influences on the caregivers' performance (Bronfenbrenner 1989). Following a discussion of the challenges faced by caregivers as they care for an individual with ASD, this chapter turns its attention to the implications of caregiving for QoL. Throughout this chapter, the significance of caregivers and families as a dynamic system and evidence from the literature are presented.

The purpose of this chapter is to inform readers about QoL in caregivers of ASD, factors that promote and impede QoL in these caregivers, and caregiver QoL in relation to ecological systems theory.

## Significance of Caregiver Quality of Life (QOL)

Quality of life (QoL) is a multifaceted construct that is defined by the World Health Organization (WHO) as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (WHO 1997). This definition encompasses a person's subjective experience of their perception of health in the midst of contextual elements. Quality of life (QoL) is a complex concept that includes many aspects of life, including **physical**, **psychological**, **independence, environment, social relations, and spirituality.** The World Health Organization (WHO 1997) designed instruments to assess QoL that incorporate the WHO definition of QoL. The WHOQOL-100 is one instrument developed by the WHO that encompasses the six domains of QoL and the 24 facets within each domain, representing key areas of QoL (Bonomi and Patrick 1997; Fig. 1).

Figure 1 outlines mediators of QoL in caregivers of persons with autism. The 56 caregiver is central in the interplay of the six domains of quality of life (QoL).

Examining QoL is crucial to research and practice as such examination may lead to comprehension of the factors that promote or impede QoL in different populations. It may also have implications for the various helping professions that work with a particularly disadvantaged population. Quality of life is strikingly germane to conditions that are long-standing and debilitating in nature, such as the wide variety of disorders on the autism spectrum. The organizational framework of this chapter (Fig. 2) is derived from the WHOQOL-100 and serves as the model for outlining mediators of QoL in caregivers of persons with ASD.

Figure 2 presents the WHOQOL-100 six domains of health and the 24 corresponding facets (Bonomi and Patrick 1997).

Though the intended use of the instrument is to measure QoL in various conditions and populations, intervention efficacy, policy development, and research, the domains and facets of the WHOQOL-100 instrument may not differ significantly from the ways in which the public view QoL and provide a foundation that encompasses aspects of caregiver QoL in ASD.

**Fig. 1** Caregiver QoL Organizational Model

## Ecological System of Caregiving

Bronfenbrenner (1989) conceptualized the ecological systems theory as the "…progressive, mutual accommodation, *throughout the life course*, between an active growing human being, and the changing properties of the immediate settings in which the developing person lives, as this process is affected by the relations between these same settings, and by the larger contexts in which the settings are embedded" (Bronfenbrenner 1989, p. 187). The ecological systems theory asserts that developmental outcomes are a result of the influence of the individual and the environmental conditions in which they live. The ecological systems theory accounts for environmental factors that act implicitly and explicitly on the caregiver and the person with ASD and describes the connection between the individual characteristics and environmental factors (Fig. 3).

Figure 3 presents the ecological framework as it relates to the domains of QoL and the central role the caregiver plays in this interrelationship.

### Caregiving Within the Ecological System

The ecological systems theory asserts that personal attributes in combination with environmental conditions influence human development (Bronfenbrenner 1989). Caregiver attributes such as age, socioeconomic status, or education in addition to

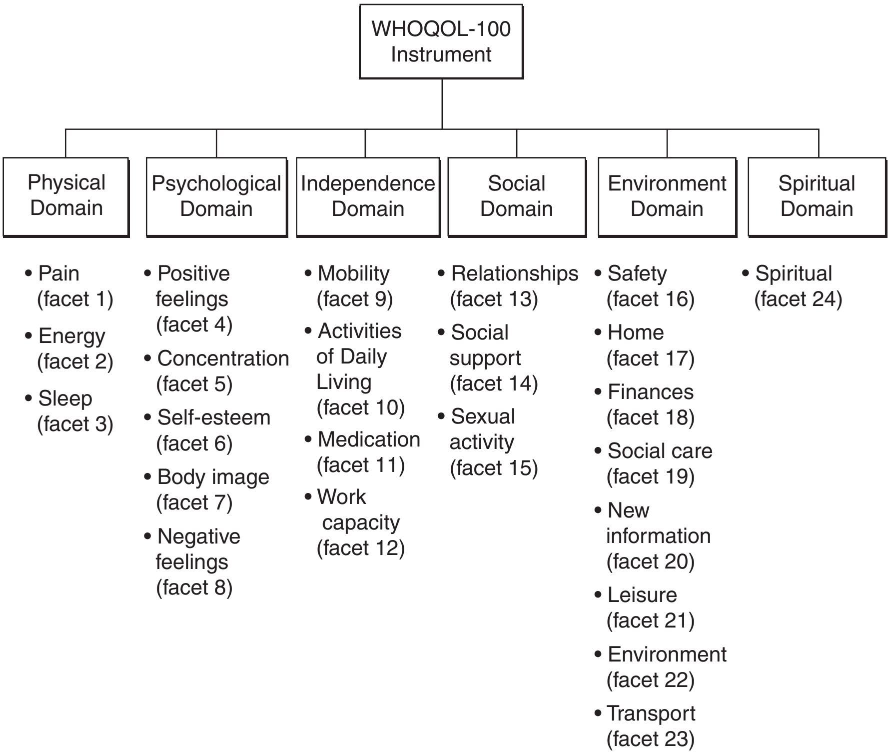

**Fig. 2** WHOQOL-100 six domains of health and the 24 corresponding facets (Bonomi and Patrick 1997). Reprinted with permission

attributes of the person with ASD such as behavior, hyperactivity, and dependence actively respond to the environment and, in turn, yield responses from the environment. Family composition in caregivers of ASD, another important attribute, ranges widely in the literature. These configurations can include two-parent families, single parents, or grandparents who provide direct, continued care to a person with ASD. Moreover, ethnic backgrounds and distribution of care (i.e., siblings) play a pivotal role in how the caregiver and person with ASD function in a small-scale environment such as home and on a larger societal or global scale. Caregivers that experience attenuating circumstances including lower socioeconomic status (SES) may be more likely to have difficulty accessing skilled health and social services (Rodrigues and Patterson 2007).

In much of the existing literature on caregivers of children with ASD, mothers are most often identified as the overseer of caregiving activities. This is also true in families of persons with a chronic condition other than ASD. Wilcock noted, “Women are particularly at risk because they often undertake a double role of domestic and paid employment occupations” (2006, p. 172). Mothers of children with chronic conditions are most notably engaged in caregiving activities that take

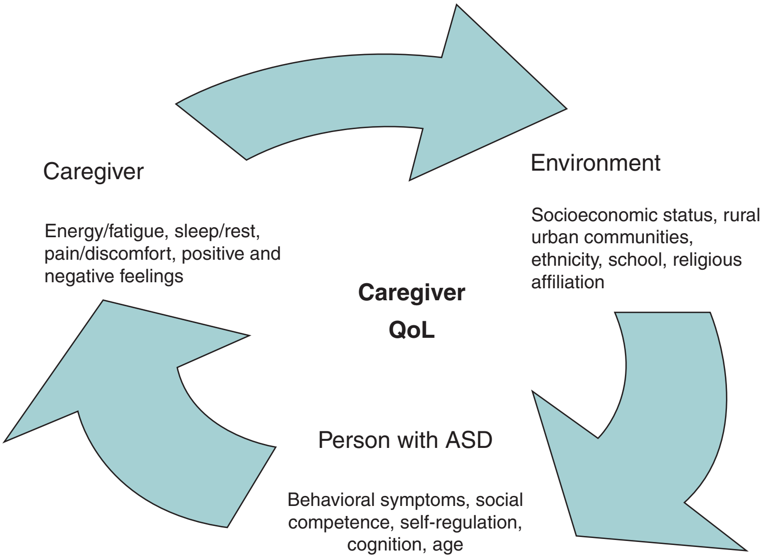

**Fig. 3** Ecological system of caregiving for person with **autism spectrum disorders** (ASD)

away time for themselves, resulting in decreased QoL (Crowe 1993; Crowe and Flores 2006). This may be due to gender inequities relating to traditional gender roles (Gray 2003). It is important to consider how spouses or those who share the caregiving responsibility characterize each others' behaviors and traits in the context of caring for a person with ASD or other chronic conditions. From an ecological systems perspective, the convergence of the multiple systems (i.e., microsystem, exosystem, macrosystem) can increase stress and demands on the family ecology. On a microsystem level (e.g., extended family, friendships), if caregiving responsibilities are increased and adequate support is lacking, stress may be amplified. For example, decreased flexibility in fathers' work schedules, fathers' work demands, and job responsibilities can increase caregiver load for a mother who assumes the primary caregiver role (Fagan and Press 2008). Managing the home, performing daily activities to sustain the health and well-being of a person with ASD, and orchestrating other responsibilities in the home consume energy and outpace the energy coming in. Insufficient support from fathers, on a microsystem level, and additional stressors including behavioral challenges or self-care dependency in a person with ASD intersect to precipitate the path toward decreased caregiver QoL.

An exosystem is a system with which caregivers are psychologically present, though not physically present (Swick and Williams 2006). While fathers may physically be at work, they are psychologically attuned to their home environment by strategizing ways to return home from work early to assist a mother in nighttime routines for a person with ASD. Mothers may sense the stress of a father's workplace based on a father's tolerance level during a time when behavioral challenges are presented by a child with ASD. Fagan and Press (2008) found that mothers experienced less work-family balance when fathers brought work stress into the home environment. The exosystem facilitates awareness of other environmental contexts without interacting with the actual environment. There is mounting evidence, however, acknowledging the significance of the role fathers represent as partners in the provision of care. Heterogeneity between mothers and fathers in their health perceptions and vulnerability to decreased QoL exists (Olsson and Hwang 2001; Mugno et al. 2007; Davis and Carter 2008).

Autism spectrum disorders result in differences in the caregiver experience and the requirements for care coordination when compared to other chronic conditions, such as cerebral palsy, Down's syndrome, or other medically fragile conditions. These conditions display observable, lucid discrepancies in overall physical, cognitive, social, and emotional functioning when compared with some of the obscure qualities of ASD including impairments in social interaction, communication, or sensory seeking behaviors. For example, caregivers of persons with these chronic conditions such as cerebral palsy or other medically fragile conditions experience increased ease with access to formal and informal supports whereas caregivers of individuals with ASD exert increased skills in agency and activism to advocate for these same formal and informal supports (Llewellyn et al. 2004). When considering supports for caregivers of individuals with ASD, the distinction in the care coordination for these caregivers can be influenced by macrosystem level interactions. Macrosystems incorporate cultural and societal influences in the caregiving role. Macrosystems can promote access to more formal and informal supports and increase care coordination in this population. For example, educational plans and programming in school environments that encourage the intellectual engagement and mastery of children with ASD aid in supporting caregivers in maximizing outcomes for these individuals later in life. A stimulating and enriching school climate is a natural by-product and contributing component to this outcome. Experiencing frustration and anger from lack of support from education consequently can increase dissatisfaction and stressors on the caregiver. A parent or caregiver support group can offer an avenue for generating mutuality among other caregivers with similar experiences in caring for a person with ASD. This provides a sense of motivation to caregivers which, in turn, compels caregivers to feel more supported and empowered in their duties as caregivers.

The caregiver balances the needs of the child with ASD with the demands of microsystems (e.g., extended family, friendships) and macrosystems (e.g., school, community, society). The caregiver and person with ASD interact constantly with these microsystems and macrosystems and respond to the corresponding aspects of these systems. For example, behaviors of an individual with ASD can fluctuate daily and the caregiver must modify routines to engender participation of the individual in daily living (Larson 2000). Behaviors such as rigidity and inflexibility in a person with ASD require the caregiver to anticipate situations that may be stressful for the child and engage in preparatory activities to facilitate success.

The individuals within the microsystems affected by this need for adaptation to routine may be significant others or spouses, siblings, or other family members who live in the home. The larger societal context, or macrosystems, may include day care, school, or disability professionals who interact with the caregiver and person with ASD outside the household. Caregivers of children with ASD engage in intense advocacy efforts (Poston et al. 2003) within these macrosystems. For example, caregivers may provide education to the public about ASD and on behalf of the person with ASD. Caregivers who take this opportunity to evoke change in the public eye and act in the role of advocate feel increased positive feelings such as self-worth in the caregiver role (Llewellyn et al. 2004). Conversely, those with impending fears of judgment and rejection perceive the act of advocacy as hopeless, which then increases negative feelings, decreased self-esteem, and unconstructive self-perceptions (Llewellyn et al. 2004).

## Caregivers of Individuals with Autism Spectrum Disorders (ASD): A Special Need

Vulnerability to decreased QoL in those who provide care for individuals with ASD is well documented in the literature (Duarte et al. 2005; Eisenhower et al. 2005; Boyd 2002). Assessing QoL in caregivers of persons with ASD cannot be thoroughly appreciated without evaluating the numerous characteristics comprising an ASD diagnosis. Caregivers operate under increased demand to sustain the needs of the person with ASD. It is a perpetual performance of managing the aspects of the disability, adapting rituals and routines, and coordinating care to regulate ongoing activities for the individual (Larson 2000). The duties of caring for a person with ASD are exacerbated by the unique qualities characterizing ASD, such as maladaptive, rigid, and stereotyped behaviors and impairments in social interaction and communication (APA 2000). The interventions available in treating the behaviors and symptoms of ASD are also arduous in nature and often require an overwhelming commitment of time and expenditure of energy on the part of the caregiver (Lounds et al. 2007). The time, effort, and demands of caregiving, as well as the constant management of roles and routines, provide a powerful argument for the assessment of QoL when examining caregivers of individuals with developmental disabilities (Allik et al. 2006; Lee et al. 2008). When considering the immensity of caring for a person with ASD, it is conceivable that QoL for those individuals, who orchestrate, execute, and provide care for a child with ASD, is jeopardized. Furthermore, caregiver QoL perceptions are often shifted to worries about the welfare of the person with ASD, which implies a relationship between caregiver QoL and the QoL of the individual for whom they provide care (Mactavish et al. 2007). As caring for children with ASD can create opportunities and barriers for caregivers' QoL, the significance of these effects on QoL is relevant for further investigation.

## Quality of Life Domains: Outcomes on Caregivers with ASD

### Physical Domain

Caring for individuals with ASD is associated with decreased physical health (Eisenhower et al. 2009; Mugno et al. 2007; Lach et al. 2009; Rizk et al. 2011). Physical health includes energy and fatigue, pain and discomfort, and sleep and rest (Bonomi and Patrick 1997). Due to the enduring nature of the caregiving role, it is plausible that aspects of their caregiving role undermine physical health. Allik et al. (2006) examined health-related quality of life (HRQoL) in parents of a child with Asperger syndrome (AS) and high-functioning autism (HFA) compared to parents of typically developing children in Stockholm, Sweden. Mothers in the AS/HFA group had lower self-reported physical health scores than mothers in the control group. When compared to the population norm in Sweden, mothers in the AS/HFA group also had lower scores than the population mean, indicative of poorer physical health. Interestingly, fathers in the AS/HFA group did not differ in physical health ratings between fathers of typically developing children when controlling for the fathers' and children's ages. Physical health scores in mothers of AS/HFA were found to be lower than the fathers of the same group suggesting an increased risk of poorer physical health for mothers. Maternal HRQoL in this study was closely linked to the severity of behavioral symptoms in the child including hyperactivity and conduct problems. This finding is consistent with previous research that behavior problems such as tantrums, self-injurious behavior, obsessive interests, rigidity, impulsivity, and unusual sensory responses make significant contributions to caregivers' stress (Lecavalier et al. 2006; Olsson and Hwang 2001; Davis and Carter 2008; Mugno et al. 2007). Caregivers of children with disabilities, including ASD, experience discernible stress stemming from the management of behavior problems as they coincide with limited social competence, inflexibility to novelty, and unusual sensory responses. The pressing needs of individuals with ASD demand that the caregiver possess adequate resources to manage behaviors as they arise. Individuals with ASD and the coexistence of behavior problems inherent in this disorder leave QoL relative to physical health an amendable target of vulnerability. Fox et al. (2002) espouse this same notion regarding problem behaviors by suggesting that the ongoing process of intervening when problem behaviors occur serves as detriment to caregiver vitality.

Somatic problems can also be manifested in the caregiving experience. Physical demands can result in pain and discomfort in the caregiver. Murphy et al. (2006) conceptualized the negative impact of physical symptoms on caregiver health. A majority of caregivers in this study reported chronic physical symptoms directly related to cumulative effects of caregiving. These included back and shoulder pain resulting from repeated lifting of their children. Though most children with ASD are ambulatory, caregivers may need to physically remove children from environments if there is a safety concern or if an increase in challenging behaviors occur. Most applicable to the ASD population, a number of caregivers described pain resulting from their children's' "…impulsive and occasionally violent behaviors"

(Murphy et al. 2006, p. 183). Older caregivers in this study described degenerative disorders including osteoarthritis from long-term effects of caregiving. Caregivers with preexisting health conditions (i.e., diabetes, hypertension) unrelated to ASD reported neglecting their own care and management of their conditions to focus on the needs of their family member. Behavior problems and decreased physical health in caregivers were also evident in a study on caregivers of children with neurodevelopmental disorders (Lach et al. 2009). The physical strain of caring for a child with a neurodevelopmental disorder coupled with behavioral issues has implications for caregiver physical health as it adds to the demand of providing care. This finding gives impetus to recognizing the significance of the physical health of caregivers of ASD; sacrificing their own personal physical health to emphasize needs of their family member can often lead to deteriorating health leaving them susceptible to chronic physical ailments and conditions. This also limits energy and maximizes fatigue to perform caregiving responsibilities.

The nature of ASD is chronic and the ongoing, irreversible, persistent essence of this disorder can create additional barriers to physical health regarding sleep and rest. There have been mixed findings on whether individuals with ASD experience sleep disturbances. Approximately 44–83 % of children with autism experience sleep disturbances (Richdale and Prior 1995). Schreck and Mulick (2000) found that children in the autism or pervasive developmental disorder (PDD) group did not differ in sleep quantity compared to other groups of children included in their study. In spite of this finding, caregivers of children in the autism group reported perceiving problems in their child's sleep quality more or greater than parents in other groups. This was attributed to parental report of increased behaviors at night waking the parent (i.e., nightmare behavior, sleep walking, and acting out dreams) either aroused or partially aroused, and interruptions in breathing patterns, or teeth grinding representative of behaviors exhibited in parasomnia (American Sleep Association 2012). Significant differences in the autism group revealed the occurrence of insomnia and parasomnia-type sleep problems. It is expected that interruptions in sleep, decreased sleep quantity, or poorer sleep quality in individuals with ASD affect sleep and rest in their caregiver. Caregivers may find themselves exhausted or sleep deprived (Murphy et al. 2006). Meltzer and Montgomery-Downs (2011) alluded to this interdependence between the caregiver and the individual as a dynamic system representing reciprocity in their relationship at all times of the day. Children with sleep difficulties, regardless of disability status, affect their caregivers' ability to acquire rest and sleep. When they awaken, their caregivers will typically awaken. This provides an additional challenge to physical health; decreased sleep and rest may impede daytime performance for these caregivers. Meltzer (2008) examined sleep quality and sleep-wake patterns in parents of children with ASD compared to parents of typically developing children, mothers of children with ASD woke 37 min earlier and slept for an average of 51 min less than mothers of typically developing children. Fathers exhibited earlier wake times and decreased sleep quantities both in the autism and typically developing group, but explanations for their earlier wake times and shorter sleep durations may have been attributed to factors unrelated to caregiving such as work schedules or stress. In a later article, Meltzer and Montgomery-Downs (2011) acknowledged the effect of developmental disability on parental sleep and rest. Caregivers' rest and sleep may be disrupted by the ongoing need to oversee and optimize sleep quality in these individuals. In extreme cases, caregivers may delay sleep to protect the individual from causing self-injury or injury to others (Ma et al. 2006). Guided by the presence of behaviors and poorer self-regulation present in ASD, it may not be ideal to allow these individuals to manage their own sleep disturbances and caregivers take control in the management of this deficit. The characteristics of the person with ASD may not support caregivers' ability to seek rest and sleep due to the need for the caregiver to manage the environmental and temporal context to promote safety and sleep in individuals with ASD. Deprivation of sleep can be related to not only quantity but their own quality of rest and sleep (Ghanizadeh et al. 2009) and are additional factors that may erode physical health.

## Psychological Domain

The self-perceptions, negative and positive feelings, and cognitive processes including thinking, learning, memory, and concentration (WHO 1997) are aspects of caregivers' psychological functioning. On a macrosystem level, disability or community professionals working with caregivers of individuals with ASD are challenged with regard to alleviation of caregiver burden particularly associated with the mental health aspect of the caregiving role. Caregivers of persons with ASD are at increased risk for decreased psychological QOL (Benson 2006; Benson and Karloff 2009; Duarte et al. 2005; Ekas et al. 2009; Hoffman et al. 2009; Lewis et al. 2006; Mak et al. 2007; Montes and Halterman 2007; Olsson and Hwang 2001; Pisula 2007; Rodrigues et al. 1990).

### Positive Feelings

The caregiving role offers opportunities for caregivers of individuals with ASD to equate positive feelings with the experience even in the midst of adversarial conditions. These positive feelings represent the resilience and adaption skills to the dynamic caregiving relationship (Humphrey and Case-Smith 2007). Velde (1997) stated, "If quality of life includes an external component and an interpretation of external conditions, then quality of life must be related to our thinking about the quality of our experience" (p. 12). While the challenges of caring for a person with ASD pose threats to QoL, a caregiver's perception of the diagnosis and the way they construe the challenges presented may offer an avenue of coping through redefinition. Tunali and Power (2002) investigated coping strategies in caring for a child with autism. Compared to mothers of typically developing children, mothers of children with autism minimized the emphasis placed on their worker role, pursued more leisure-related activities, considered others' opinions of child's behavior less, appreciated spousal support and significance of parental roles, and developed more tolerance for ambiguity (Tunali and Power 2002). In relation to QoL, when caregivers reconstruct their experience by focusing on the uniqueness of raising a person with ASD, they can change a dissatisfying experience to extract satisfaction and increase self-esteem and self-efficacy, resulting in improved psychological QoL. Psychological factors are also associated with caregivers' perceptions about the influence of the person with a disability. When caregivers redefined their coping strategies, this was found to shape positive perceptions of their caregiving experience in mothers of children with intellectual disabilities. In a study investigating maternal perceptions in caregiving of children with intellectual disability (ID), modifying mechanisms by which mothers coped with the impact of the child with ID were associated with positive perceptions of their child. Psychological adjustment, use of social supports (including relationships with other caregivers, friends, and family), and self-enhancing qualities such as personal growth were contributing factors to mothers' positive perceptions of their child. In persons with ASD, caregivers may find this experience as a way to promote personal growth and maturation. (Hastings et al. 2002).

Lounds et al. (2007) explored maternal well-being during a different developmental stage of life in their investigation of transition and change in adolescents and young adults with autism. Whereas Allik et al. (2006) used a sample of young, school-age children in their study of QoL in caregivers, Lounds et al. (2007) chronicled a time period in which individuals with autism are likely to undergo major marker events. Adolescence is a remarkably perplexing and stress-inducing time in caregivers and their children, both for those who are typically developing and those with disability. Caregivers experience new concerns as their children enter the adolescent phase of life. The context in which the caregivers and children interact may typically be more forgiving or emphatic in the early childhood and school-age years, but as these individuals transition out of early childhood and school-age years, deficits may appear magnified and become less obscure. Accepted behaviors in childhood become glaringly poignant and less tolerable in adolescence (Humphrey and Case-Smith 2005). Compounded with the intricacies of this life stage, a caregiver of a person with ASD is dually challenged in trying to transition this individual through developmentally appropriate activities. Lounds et al. (2007) described a number of these developmental events including exiting the school system, increasing behavioral challenges leading to prescription of psychotropic medication, and changes in hormonal balance and heightened sexual needs (Humphrey and Case-Smith 2007). Positive life transitions such as exiting high school, attaining higher education, or gaining sheltered employed yielded an increased sense of QOL in caregivers. This increased QoL was also coupled with the decline of challenging behaviors managed by medication and improved quality of relationship between the caregiver and person with ASD (Lounds et al. 2007). This demonstrates how environmental conditions, specifically on a macrosystem level (i.e., formal education system, employment), act together with personal attributes and on a microsystem level (i.e., relationship between caregiver and adolescent/young adult) in shaping developmental outcomes. The multiple system levels embedded in the ecological model and the interrelationship of these systems promote increased QoL for caregivers.

### Negative Feelings

In spite of the research devoted to the positive outcomes of caring for an individual with ASD (Tunali and Power 2002; Hastings et al. 2002), it is still noteworthy that caring for an individual with ASD can produce a qualitative difference in caregiver QOL. Caregiving is associated with decreased psychological well-being. The caregiving experience can create negative effects on psychological functioning. In most QoL research, mothers' impaired psychological functioning is associated with the emotional, behavioral, and cognitive issues of persons with ASD. Ma et al. (2002) studied a group of parents of children in Hong Kong with emotional or behavioral problems. Mothers in this study were most affected by the child's emotional or behavioral problem, but siblings and fathers also were shown to experience negative impacts on psychological well-being. These included feelings of "…irritation, sadness, distress, worry, anxiety, fear, fatigue, and loss of control" (Ma et al. 2002, p. 102). In mothers who participated in this study, psychological impairment began to manifest itself through somatic symptoms such as "…numbness of limbs and dizziness" (p. 102). Conversely, fathers in this study displayed more passivity and a "let it be" (p. 102) mentality regarding the child's problems. Fathers attributed the child's problems to genetic influences stemming from other members in the family who displayed similar deficits as the child. The mention of this generational belief system served as a coping mechanism possibly utilized to decrease burden and inconvenience caused by the child's behavioral and emotional issues. Marital discord was also evident in the study. Mothers and fathers experienced tension in their relationship, particularly around their differing stances on ways to cope with their child's behavioral issues. This was also evidenced in a study on gender and coping of parents of children with high-functioning autism (Gray 2003). Child impairments served as a basis for confrontation between the mother and father and increased strain on the marital relationship (Gray 2003). These findings are of particular importance given the evidence that spousal support, in particular, is linked to reduction in stress and depression in caregivers of children with ASD (Dunn et al. 2007; Higgins et al. 2005; Kuhaneck et al. 2010; Sawyer et al. 2010). Shin et al. (2006), in their study on parenting stress in mothers and fathers of young children with cognitive delays in Vietnam, reported that mothers, as expected, were most affected by the cognitive delays in their children. Maternal stress was highest in mothers of female children, children with lower cognitive functioning, and those with spouses with poorer health. The study also noted that the observed impact on mothers was in part due to the traditional gender roles of mothers bearing greater responsibility for caregiving. Fathers in this study experienced more stress associated with lower SES and an inadequate level of social support. Another association was made between the variables producing stress in fathers; lower SES and social networking were more important in the paternal role and the way in which the familial unit relates to those in the larger social context. In addition, fathers may also play less significant role in the child-rearing experience of children with disabilities (Shin et al. 2006).

## Environment

Facets of the environmental domain of QoL include financial resources, accessibility and quality of health and social care, home environment, and participation in leisure and social activities. Additional facets include safety, new skill or information acquisition, and physical environment (i.e., noise, pollution, and climate). Caregivers, specifically mothers of children with disabilities, were more likely to be unmarried with limited education and participation in paid work (Witt et al. 2003). Having an individual with ASD in a family may direct the way in which the environment serves as a barrier or creates opportunities for QoL.

For example, individuals with ASD receiving intensive in-home therapy or services in the community (accessibility of social care) may require the caregiver to modify their work schedule, remain unemployed, or stop working to be at home to sustain caregiving responsibilities. Leaving the worker role may not always be the ideal circumstance for caregivers, but responsibilities and obligations of caring for a person with ASD can interrupt their ability to perform duties in the worker role (Ma et al. 2002). Work loss, to any degree, whether decreasing workweek or leaving the worker role, create challenges to financial resources for caregivers (Ghanizadeh et al. 2009). This financial burden is also the case when considering the unpaid nature of the caregiving role and the resulting diminishing access to the financial resources of paid work, despite caregiver reimbursement from state institutions (Gahagan et al. 2007). This poses an added risk to QoL with decreased access to economic resources. Caregivers with more education (accessibility and quality of health and social care) and higher incomes (financial resources) also optimize environmental resourcefulness. They may possess the knowledge and accessibility to health and social care for the individual with ASD leading to increased family functioning (Rodrigues and Patterson 2007; Ma et al. 2002). It is easy to surmise that these factors are natural by-products as well as contributing factors to increased QoL, not only on behalf of the caregiver but on the care recipient. Again, this demonstrates the dynamic system between the caregiver and care recipient, in this case, the individual with ASD.

The primary language of the caregiver may create a barrier to high quality and accessible health and social care. Caregivers of persons with a disability or impairment are challenged in their need to obtain skilled services or other formal support. Challenges in accessibility may be exacerbated when English is a second language. Poston et al. (2003) found that parents of children with disabilities where English was not their primary language experienced difficulty with accessing services and supports such as educational rights, insurance, and paying for health care. Caregivers, as activists and in assuring agency in the public domain, can feel challenged by larger systems of health and service care, especially whose job it to support these individuals and their caregivers. The need for professionals to listen, show respect, and apprehend caregivers' needs contributes to QoL. Increases in frustration and barriers to service systems were debilitating at times more so than the stress of meeting special needs of the individual in whom they provide care (Poston et al. 2003; Renty and Roeyers 2006).

**Table 1** Individual and family characteristics of the overall sample

| Characteristic | Sample ($n = 33$) | Percentage (%) |
|---|---|---|
| Age of mother (years) | | |
| Mean | 38.6 | |
| Minimum | 27 | |
| Maximum | 49 | |
| Age of child with autism (years) | | |
| Mean | 7.4 | |
| Minimum | 3 | |
| Maximum | 18 | |
| Marital status | | |
| Married | 30 | 90.9 |
| Divorced/single | 3 | 9.1 |
| Employment status | | |
| Employed (full time/part time) | 21 | 67.7 |
| Not employed | 10 | 32.3 |
| Number of children | | |
| One child | 8 | 24.2 |
| Two children | 18 | 54.5 |
| Three children | 7 | 21.2 |
| Median | 2 | |
| Birth order of child with autism | | |
| Oldest/only | 21 | 63.6 |
| Middle | 2 | 6 |
| Youngest | 10 | 30.3 |

Note: Not all percentages equal 100 % because of unreported data by mothers and rounding

## Leisure and Recreational Activities

Participation in leisure and recreational activities can directly influence QoL. Engaging in leisure activities may constitute barriers for caregivers of individuals with ASD. Substantial amounts of time performing caregiving duties may interfere with time spent in discretionary activities. Meaningful and enriching leisure activities can facilitate feelings of self-control and identity, serve in the ventilation of increased stress, and promote feelings of worth and creativity.

Rizk, Pizur-Barnekow, and Darragh (2011) conducted a study on leisure and social participation and health-related quality of life (HRQoL) in caregivers of children with autism (Table 1).

Table 1 lists the demographic data of the individual and family characteristics of the overall sample (Rizk et al. 2011).

Health-related quality of life (HRQoL) describes an individual's perception of their physical and mental health (Centers for Disease Control and Prevention 2012), while QoL refers to overall health and well-being including physical, psychological, independence, social, environmental, and spiritual aspects of

**Table 2** Association between participation in social and leisure activities and health-related quality of life (HRQoL)

| Measure | Physical component score (PCS) | | Mental component score (MCS) | |
|---|---|---|---|---|
| | r | p | r | p |
| Overall activity participation | −0.105 | 0.562 | −0.066 | 0.714 |
| Sports/physical activities/nature | −0.206 | 0.284 | −0.060 | 0.758 |
| Hobbies | −0.421 | 0.015[a] | 0.032 | 0.858 |
| Crafts | −0.286 | 0.344 | −0.226 | 0.458 |
| Games | −0.015 | 0.948 | 0.294 | 0.184 |
| Sociocultural/entertainment | 0.006 | 0.974 | −0.130 | 0.485 |
| Community/education | −0.392 | 0.036[a] | 0.251 | 0.189 |

[a] Correlation is significant at the 0.05 level

health (WHO 1997). They found that mothers of caregivers of children with ASD who participated in a higher proportion of hobbies and community/education activities experienced decreased physical HRQoL (Table 2).

Table 2 presents the correlations between leisure and social participation and HRQoL from the SF-12 in caregivers of children with ASD (Rizk et al. 2011).

Caregivers in that study were more likely to engage in more sedentary, passive types of leisure activities. Passive leisure activities may be more accessible for caregivers of individuals with disabilities. These activities require low energy expenditure and short duration, and can be spontaneously performed or discontinued at any time (O’Mullan Wayne and Krishnagiri 2005). Caregivers who perceive themselves as less physically healthy may gravitate towards more sedentary types of leisure which may not promote physical health. Moreover, participation in community/education activities such as charity work, attending classes, or civic groups may be additional demands on caregivers’ time when considering the time spent by caregivers of children with disabilities (Crowe 1993; Crowe and Florez 2006; Johnson and Dietz 1985). It is expected that these factors may contribute to decreased physical health in caregivers of ASD.

Fenech (2008) states, “Encouraging leisure gives opportunities to experience self-efficacy, self-worth, creativity, and self expression with unengaging leisure being significantly related to negative mental health outcomes” (p. 295). The caregiving experience of ASD may create a barrier to participation of leisure and recreational activities. Aspects of leisure and recreational participation dissipate caregivers’ participation such as perception of the social stigma received from others, accessibility of the activity in consideration of needs, abilities, and skills of the person with ASD, and the extenuating toll of participation in discretionary activities of the caregiver (Fenech 2008; Humphrey and Case-Smith 2005). Gahagan et al. (2007) examined the impact of leisure on women’s health in Nova Scotia, Canada. Several themes emerged from the findings of this research that may draw a parallel between this group of women and caregivers of individuals with ASD. The women in the study placed significant emphasis on their caregiving role both as an expectation constructed socially and embedded in their self-identity. Though this group of women was not caregivers of individuals with disabilities, they share the same sentiment in terms of barriers and opportunities to leisure and recreational engagement. Lack of resources such as financial, temporal, and transportation, support (arranging for care in their absence), role demands, and social networks were viewed as critical elements in the pursuit of leisure. These same elements can serve as a basis influencing participation for caregivers of individuals with ASD. Gevir et al. (2006) compared the time use between mothers of children with and without disabilities. The results of that study indicated that mothers of typically developing children and those with disabilities spend a substantial amount of time acting within their worker role. Work demands, fatigue, and caretaking are factors that consume caregivers' time to engage in discretionary activities (O'Mullan Wayne and Krishnagiri 2005). Finding trustworthy care providers or quality respite for individuals with ASD was part of planning and scheduling needs that were prerequisites to engagement in leisure activities (Mactavish et al. 2007). Nonetheless, the eminent repercussions of limited participation in discretionary activities on the physical, cognitive, and psychological well-being of caregivers have been recognized (Stevens et al. 2004). Delineating boundaries and purposefully switching attention from supporting the individual with ASD to priorities to nurture oneself can sustain caregiver QoL.

## Level of Independence

### Activities of Daily Living

Habits and routines are embedded in the contextually enriched experience of daily living. In a familial context, the abilities and needs of the person with an ASD may result in changes to the daily rituals and routines governing everyday living. Medication routines may need to be established to ensure that prescribed medications for symptom control are taken regularly, especially in adolescence and young adulthood (Lounds et al. 2007).

Larson (2000) conducted a study on the establishment and utilization of routines in families of children with autism. The hallmarks of an ASD diagnosis necessitate a preference for routines. This characteristic of an ASD diagnosis, the rigidity and insistence on consistency in daily activities, was found to produce increased parenting stress among those coordinating the needs of the family with that the person with ASD. As routines were established, the organizational framework of the household increased the flow of these routines. Furthermore, routines aid in smoothing transitions and regulating a person with ASD's anxiety and the onset of challenging behaviors. The routines established are also an additional asset to increasing adherence to parental expectations and provides a sense of predictability and security throughout their day. Routines, the template by which activities and tasks are embedded, help to regulate familial systems and foster an increased sense of predictability and reduces conflict of competing external forces threatening patterns of routine (Humphrey and Case-Smith 2007). This is especially relevant for individuals with ASD, for whom tolerance for ambiguity and unpredictability is low. Although adherence to routine has been shown to increase participation, routines may also inadvertently bolster the individual's inflexibility to change when unexpected circumstances arise. The mother's work to produce functional, non-stressful routines and minimize performance anxieties was complicated by the child's inability to endure change. Mothers described this as "...a barrier to improvisation required in daily life" (Larson 2000, p. 73).

### Dependence on Medicinal Substances and Medicinal Aids

One aspect important to caregiver and family health was adherence to medication protocols. The time medication was administered correlated with the child's increased capacity to perform at their optimal level as the medication controlled their symptoms. Similarly, when the medications began to wear off, this dictated another alteration in routine as children's hunger and sleeping needs increased. In relation to a person with ASD, increased prescription of psychotropic medications elicited decreased behavioral challenges impacting the likelihood that caregivers perceived management of the diagnosis more tolerable (Lounds et al. 2007).

Fiese (2007) examined the importance of establishing routines and rituals as a catalyst for participation in family health related to medication protocols. Though the sample in the Fiese (2007) study was comprised of children with respiratory conditions (i.e., asthma), the significance of medication management is validated in use of persons with ASD. ASD, as with other chronic conditions such as asthma, may not be curable, but management of the symptoms through adherence to medication protocols may offer opportunities for increased health and well-being for the person living with the condition. As evidenced in the study on adolescents and young adults undergoing a period of transition and change (Lounds et al. 2007), medication served as an indicator of decreasing behavioral challenges and promoted residual effects in the quality of the relationship between caregivers and the person with ASD. For effective management of symptoms for these individuals, psychotropic medication was a mediating factor. A consequence of decreased adherence is increased behavioral challenges and latter effects on caregiver functioning such as participation in work, discretionary activities, and effects on physical health (Ma et al., 2006, Fox et al. 2002; Poston et al. 2003; Murphy et al. 2006). Related to psychological well-being, Gray (2003) found that mothers of children with high-functioning autism additionally relied on the use of prescription medication to alleviate emotional distress related to their child's autism.

## Social Relations

Social relations and a symbiotic relationship between caregivers and the external world promote sustainability, success, and mutual satisfaction. It is another factor associated with caregiver QoL. That inadequate social support leaves caregivers vulnerable to decreased psychological QOL including stress, anxiety, and depression has been well documented in literature (Barker et al. 2011; Boyd 2002; McGuire et al. 2004).

Social support is a venue in which caregivers are provided enriched opportunities for growth and expansion of relationships with others. Mesosystems, relating two or more systems by which a family interacts, demonstrates Bronfenbrenner's theory of the importance of relationships with others and the family ecology (Swick and Williams 2006). Extending circles of interaction beyond the dyad of the caregiver and person with ASD to the community fosters increased possibilities for enhancing QoL. Cultivating community with others gives recognition to the significance of the dyadic relationship of caregiver and person with ASD within the vast web of a mesosystem. Emphasizing those relationships between caregiver and person with ASD with the mesosystem is mutually reinforcing in considering how this dyadic relationship also influences a mesosystem. Allowing systems, microsystems and mesosystems, to exchange lenses and observe these systems in their domain to understand their mental framework guiding decision-making, child rearing, and daily life present in these various families. For example, a caregiver may be resistant to attending social functions due to concerns of acceptance and inclusion of the person with ASD. Acceptance of the person with ASD has substantial effects on QoL. The societal forces that may influence the opportunities for seeking social support can generate underlying challenges and perhaps even withdrawal when a caregiver interprets a social context negatively. Having a person with ASD in a family can adversely affect caregivers' social relationships with others. Caregivers of individuals without disabilities may lack the knowledge in how to interact with the person with ASD. It is particularly important for caregivers to connect with other caregivers of ASD because of their shared experience (Tunali and Power 2002). Therefore, individuals who serve as social support for caregivers must also exhibit a similar sense of caring and nurturance in their relations with the person with ASD (Swick and Williams 2006). The challenges associated with arranging care for the individual and the planning of quality respite decreases opportunities caregivers have to socialize. Individuals with ASD who also have increased behavioral challenges may also not be exposed to social situations frequently to avoid the negative reactions from others.

The relationship between social supports from health care providers as opposed to family, friends, and other community members is unclear. In one study (Hassall et al. 2005), mothers were found to report lower levels of caregiving stress when able to access social supports. In particular, informal social supports (i.e., relationships with other parents, friends, and family) were found to be more beneficial to mothers (Hastings et al. 2002) than more formal support systems such as community or health-related professionals. One explanation is that health-related professionals may not always have the ability to offer positive perspectives of the caregiving experience in the way that other family members, friends, or other parents can. Conversely, the use of formal supports has been shown to result in improved coping mechanisms, sense of coherence, resilience, and stress as found in a study on, others' stress and resilience in the context of participation in an early intervention program (Margalit and Kleitman 2006). After participation in an early intervention program, mothers were found to have a higher sense of coherence and improved coping mechanisms, were able to view themselves as agents of change, and possessed an increased sense of empowerment to cope and manage stressful situations (Margalit and Kleitman 2006).

## Spirituality/Religion/Personal Beliefs

Spirituality and religious beliefs can serve as mechanisms to combat decreased QoL in caregivers when they feel depleted. Spiritual or religious beliefs may be influential or impartial considerations in caregiver QoL related to ASD. Caregivers may experience difficulty with managing deficits in behavior, emotional responses, cognitive functioning, and delays in development. In an act to alleviate the mystery and dissonance of ASD, caregivers may invoke spiritualistic rituals to circumvent the inclination to surrender to the disparity of resources and solutions to provide optimal care for the person with ASD. Affiliation with religious organizations may also be a mediating factor in increasing caregiver QoL by reducing stress (Bayat 2007; Boyd 2002; Gray 2006; Luther et al. 2005). However, though affiliation with religious organizations can be viewed as means to increase self-esteem, participation in religious activities also may result in increased depression (Ekas et al. 2009). Reliance on religious or spiritual support is also evident in caregivers who feel a loss of control over their child (Cappe et al. 2011).

As in the case of the parents in the study on parental distress in Hong Kong (Ma et al. 2006); two parents in this sample turned to superstition and prayer to remedy emotional and behavior problems. They performed activities that they deemed beneficial in ridding their child of their impairments such as placing pictures in the home environment that would "…drive away the 'dirty things,' that is ghosts and devils" (Ma et al. 2002, p. 103). Spiritualistic activities also included inviting religious specialists to their homes to conduct ceremonies for the person with emotional and behavior problems. Nevertheless, these were strategies caregivers appraised as useful in supporting their experience and ultimately produced decreased distress affecting psychological QoL.

## Summary

The caregiver role of individuals with ASD embodies the direct and indirect experience of supporting persons with this diagnosis. Caregivers balance physical, psychological, environmental, social, spiritual, and independence facets of QoL. Combining awareness of the inner experience of QoL to the outward expression of QoL cultivates cognizance of the factors limiting and creating opportunities for increased QoL in this population. The concepts outlined in this chapter promote understanding about the caregiving experience influential on QoL outcomes.

The dynamic system comprising the caregiver relationship with the person with ASD serves as a reference point in how QoL is instrumental in functioning as a basis of quality care for individuals with ASD and as outcome of provision of care.

## Key Terms

*Caregiver*. a person who spends a substantial amount of time organizing, sustaining, and managing day-to-day activities and assists with functioning and producing optimal developmental outcomes on a continuous basis.

*Coherence*. feelings of balance and control of self and that environmental conditions will produce optimal outcomes.

*Ecological system theory*. conditions and qualities of an environment produce various developmental outcomes dependent on personal attributes and background of person.

*Parasomnia*. interruptions in sleep exhibited by nightmares or night terrors, talking in one's sleep, and sleepwalking.

*Quality of life (QoL)*. a person's subjective experience of their perception of health in the midst of contextual elements and includes many aspects of life, including physical, psychological, independence, environment, social relations, and spirituality.

## Key Facts

- The caregiver role of individuals with autism spectrum disorders (ASD) has implications for quality of life (QoL) that can be a manifestation of overall health and well-being.
- Quality of life is a construct relevant in consideration of populations where conditions are chronic in nature and can provide insight to professionals on the phenomenological experience of this population.
- From an ecological perspective of caregiving, the caregiving relationship (i.e., caregiver and person with ASD) functions collectively with environmental influences and shapes developmental outcomes through this relationship.
- The role of the caregiver of the person with ASD is significant in providing quality care and organizing daily living making this role of interest in examining QoL.
- Attributes of the person with ASD such as behavior problems, intellectual disability, and overall dependence can create challenges or provide positive outcomes regarding caregiver QoL.
- Physical, psychological, environmental, social relations, leisure participation, and spirituality are aspects of QoL that present opportunities and barriers to caregiver QoL in individuals with ASD.

## Summary Points

- This chapter focuses on quality of life (QoL) in caregivers of persons with ASD, factors contributing to QoL in these caregivers, and the relationship of the caregiving experience to the ecological systems theory.
- Quality of life domains including physical, psychological, environmental, social relations, leisure, and spirituality contribute to caregiver QoL in individuals with ASD.
- The dynamic relationship between personal attributes (caregiver and person with ASD) and environmental influences that shape developmental outcomes and relate to caregiver QoL.
- Awareness of contributing factors to caregiver QoL in persons with ASD lays the foundation for creating opportunities to increase QoL.
- Information on factors that contribute to caregiver QoL also provide predictors of quality care of the person with ASD.

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