



Typically Developing Children and Their Impact on Parental Caregivers' Quality of Life: Literature Review

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Introduction

Several studies have addressed the demands placed on caregivers and how these demands increase stress and impact the caregiver's quality of life. In order to assess influential factors of quality of life through scholarly research, additional factors can be further explored and narrowed to pinpoint the specifics through which quality of life is affected. Because of individual differences, it would be virtually impossible to identify each and every contingency affecting one's well-being. However, by scrutinizing factors that are known, the quest to assess the when and for whom is a legitimate and logical next step in this endeavor. Databases used in this search included ProQuest, EbscoHost, Medline, Mental Measurements Yearbooks, and additional websites and books relevant to caregiver stress, perception of parenthood, and quality of life. Keywords used in the search included caregiver stress, parental caregiver stress, quality of life, caregiver quality of life, perception, perception of parenthood, life satisfaction, and parenting. To illustrate what is currently known, the following areas were critically reviewed: stress, caregiver stress, the role of other family members, income and utilization of community resources, perception of parenthood, and quality of life.

Stress

Stress encompasses a complex set of reactions in response to a perceived threat to one's well-being or pressure to adapt to one's circumstances [1]. The occurrence of stress is common and can enter a person's life at any time. When stress occurs from one's relationships, it is called social stress. There are three main social stressors [2]: life events (abrupt life changes that require a quick adaptation); chronic strains (persistent events that require adaptation over an extended period); and, daily hassles (minor events that require recurring adaptations on each day). Therefore, the stress-coping mechanisms vary and are instrumental in one's adjustment to stressful circumstances. However, when stress becomes chronic, an individual experiences emotional, behavioral, and psychological changes, which in turn increase the risk of mental disorder and physical illness.

In assessing therapeutic benefits, coping strategies, as well as reactions to stress, individual differences must be considered. When challenged under the same or similar circumstances, there is no

guarantee individuals will react or respond to stressors in the same manner. However, Lehrer, Woolfolk, and Sime [3] reported individuals tend to appraise their circumstances consistently based on the demands of the situations they encounter and their ability to cope with those demands. Therefore, the perception of stress is determined by both the situation itself (external cues) and one's individual interpretation or appraisal of the situation (internal cues).

The physiological signs of stress include two interrelated systems known as the sympathetic-adrenomedullary (SAM) and the hypothalamic-pituitary-adrenocortical (HPA) axis [4]. When individuals perceive situations as being threatening or harmful, the cerebral cortex sets off a chain of events related to that belief. Information is transmitted from the cerebral cortex to the hypothalamus which creates the immediate response to stress which includes sympathetic nervous system arousal, or the fight-or-flight response. This arousal leads to symptoms involving an increase in blood pressure, heart rate, sweating, and constriction of peripheral blood vessels. Once the HPA system becomes activated, the hypothalamus releases corticotrophin-releasing factor (CRF) which stimulates the pituitary gland to secrete adrenocorticotrophic hormone (ACTH). The ACTH then stimulates the adrenal cortex to release chemicals called glucocorticoids. Two of the most significant of these hormones are cortisol and adrenaline. Cortisol acts by reducing inflammation in case a person is injured in addition to helping the body to return to its balanced state following stress whereas adrenaline is commonly associated with the fight-or-flight response is activated during perceived threat and danger. Cortisol also works by inhibiting functions that are nonessential in a fight-or-flight situation by altering one's immune system responses and suppressing the digestive system. Any change within bodily systems that occurs during the stress response is communicated with the brain; more specifically the hypothalamus and the limbic system, which controls emotions and memories. Once a threat is over, adrenaline and cortisol levels should return to normal, in conjunction with the immune system, blood pressure and heart rate. Unfortunately, under times of chronic stress, these hormones are constantly heightened and the fight-or-flight reaction remains activated. This eventually strains bodily processes and put the individual at risk of numerous health issues such as heart disease, digestive problems, weight gain, anxiety,

and depression [5,6], all of which can negatively impact one's quality of life.

If an individual is faced with repeated stress, the functioning of the HPA system may become altered and malfunction. The signs of stress may include elevated levels of awakening cortisol which may extend long into the afternoon or evening [6], a general lowering of daily or diurnal rhythms, an exaggerated cortisol response to a challenge, a lingering cortisol response following a stressor, or simply no response at all. As a norm, diurnal rhythms of cortisol suggest this hormone is at its highest level first thing in the morning with decreases beginning in the afternoon until reaching a low-point in the evening [6]. When there are disruptions in this pattern, insufficient or overabundant levels of cortisol make it more difficult to respond to and recover from stress and even more so when the end result is mental impairment. The link between cortisol and depression is well documented with cortisol serving as a predictor of major depressive episodes [1,5,7].

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Perhaps most commonly known is the association between cortisol and another stress-related disorder known as post-traumatic stress disorder (PTSD). According to Yehuda [8], exposure to extreme levels of stress increases the amount and sensitivity of cortisol (glucocorticoid) receptors in the brain which in turn regulate cortisol secretion.

In an exhaustive literature review, Herbert [5] sought to better understand the role cortisol plays in the development of major depression. When diurnal rhythms are disturbed, there is a build-up of cortisol which in turn may induce major depression. Although elevated levels of cortisol can occur throughout the day, those at highest risk of major depression are those who have a higher level of cortisol immediately after waking. This is identified as the post-awakening cortisol surge [5]. Findings from the review revealed cortisol is a contributing factor to variations in genetics for the risk of major depression and the way in which environmental events magnify that risk [5]. From these results, Herbert [5] concluded the role of cortisol needs to be addressed in a clinical context by clarifying and distinguishing between specific subtypes of major depression (e.g., single episode, recurrent episode, catatonic features, melancholic features, atypical features, and postpartum onset) and how each is affected by the time in which elevated levels of cortisol occur within the individual. This in turn would be useful in identifying those who would most likely benefit from cortisol blockades as a treatment of major depression as well as a preventative measure [5].

Stress in any form can be a detriment to an individual's health by breaking down his or her immune system leading to the susceptibility to certain illnesses such as hypertension, and cardiovascular disease [4]. This is based on the allostasis theory of stress postulated by McEwen [9]. The term allostasis refers to how the cardiovascular system functions as it adjusts to different bodily activities and literally pertains to the maintenance of stability through change. Allostatic load develops whenever there is insufficient recovery of chronic

stress resulting in wear and tear on the body. This can occur when the demands of the environment exceed the ability to cope, thus making the return to homeostasis much more difficult. When stress and stress-related illnesses occur, many factors may contribute to their onset, including but not be limited to the type of stressor, the length of its duration, and the use of sufficient coping mechanisms [4].

Although there are various causes of stress, some are acute (e.g., having a car run a red light), others, such as caregiving for a loved one, are chronic. In the case of acute stressors, the body should return to a state of normality soon after the stressor is removed. In contrast, the ability of the body to recover from chronic stress is far more difficult as the continuous presence of the stressor makes the individual more susceptible to both mental and physical illnesses such as major depression, anxiety disorders, and cardiovascular disease [4, 5]. Because of the chronic nature of caregiving stress, the potential for illness is magnified when compared to those outside of this population [10,11].

The physiological responses to stress discussed show a direct relationship between stress and other mental and physical health conditions (e.g. heart disease, digestive problems, weight gain, anxiety, depression, hypertension, and PTSD). The presence or the occurrence of perceived stressful situations lead to these conditions and can negatively impact the quality of life of those affected. One such situation that may lead to the occurrence of the aforementioned health conditions is the perceived burden and stress associated with caregiving for someone with a special need.

Caregiver Stress

Stress can occur as a response to many stimuli including being in the role of caregiver for others, be it as a parent or as a custodian of someone unable to care for themselves due to illness or disability. This phenomenon is commonly known as caregiver stress [12,13,14]. When a caregiver becomes overburdened with having to care for someone whose condition is of a chronic nature, the caregiver's quality of life is compromised due to the stress associated with this role [14]. To address the ramifications of caregiver stress, characteristics and habits of the caregiver are discussed in order to provide insight into who within this population is more susceptible to the detriments of caregiving. The specific areas discussed include (a) health status of caregivers, and (b) consequences of caregiving.

Health Status of Caregivers

Caregivers affected by child's condition may not perceive their subjective issues to be stemming from their children or they may simply ignore the issues all together until a major crisis such as illness occurs. Even then, some parents may not make a connection between their situation and that of the child. Unless these parents recognize their symptoms and subsequent illness as possible products of circumstances occurring with their child, they may ignore or overlook a major area of assistance such as available resources and support from other parents in similar situations (from which they may strongly benefit). Once a child is known to have a particular illness or handicap, parents may wonder what options are available to them with respect to the care of their child. Unfortunately for some, they may not realize or recognize that their individual needs should be attended to as well. When a parent is challenged with the rearing of a physically or mentally disabled child, the use of available resources and support services would likely make this endeavor less stressful.

The mental and physical well-being of caregivers is vital to their capacity to care for those in their charge. If the caregivers are in poor health, their own health and their ability to care for others could be drastically exacerbated by the effects of caregiver stress [15]. This realization is what led Bruce et al. [15] to investigate whether physical health problems of the caregiver contributed to caregiver stress. In their study, 91 identified caregivers were assessed to determine whether their health condition factored into their experience of stress and their reduced ability to care for the family member in need.

Measures used in the assessment included the 12-item version (SF-12) of the Medical Outcomes Study Short Form Health Survey which yields both a mental component summary (MCS) score and a physical component summary (PCS) score as a result of mental or physical health problems. Results indicated 76.9% of the participants reported having experienced stress; 72.4% reported having medical conditions; and 67% were reportedly taking medication. Scores on the MCS were significantly lower than community norms which indicated an excess of disability associated with mental health problems. Scores on the PCS indicated 40.7% of the participants had some degree of physical disability. These results led the researchers to conclude caregivers of persons with dementia should be assessed for disabling physical conditions and mental health problems. Further, the aforementioned study suggests the mental and physical health of the caregiver is extremely important in evaluating the likelihood of experiencing stress when caring for a mentally and/or physically deficient child. One limitation of this study, however, is the fact results were based on present reporting which leads to the question of whether issues were present prior to taking on caregiving responsibilities or after. A longitudinal cohort design would likely shed more light on this.

When assessing the value of coping strategies, DiMattei et al. [16] conducted a study in which the goal was to investigate if caregivers' physical health and the severity of the patient's condition are significantly associated with higher levels of distress in the caregivers of elderly dementia patients. The researchers hypothesized (a) a somatic disorder in the caregiver is associated with a significant increase in burden of distress and (b) the use of a coping style that minimizes or avoids the stressor may actually predispose caregivers to higher levels of burden of distress [16]. Comparisons were made between the caregivers' levels of distress and how such distress related to the coping strategies they adopted.

The study was conducted using a sample of 112 caregivers who provided primary assistance to a single family member patient who suffered from dementia. Patients were all admitted to the Neurological Ward of San Raffaele-Turro Hospital in Italy between the periods of December 2004 and June 2006. Caregivers of these patients included 82 women and 30 men with a mean age of 58.94. Fifty percent of the caregivers were caring for a parent, 41.1% were caring for a spouse, and the remaining 8.9% had other relationships with the person they were caring for. Caregivers were given a set of questionnaires that included the Caregiver Burden Inventory (CBI) which includes five subtests of time dependence, development burden, physical burden, social burden, and emotional burden. From these five subtests, three factors were extracted to serve as dependent variables. The first factor reflected emotional exhaustion, impairment of caregivers' health and general functioning; the second factor reflected emotional distress in the caregiver and the impact of caregiving on the family; and the third and final factor emphasized the patients' dependence on the caregivers' support and the time demands and restrictions caregiving demands.

One of the statistical analyses used in this study was a factor analysis on the correlation mix of all CBI items which resulted in the three factors identified previously. This analysis showed a satisfactory internal coherence (Cronbach's alpha: 0.89, 0.74, and 0.85). A multivariate analysis of variance (MANOVA) was also conducted to determine the impact of the caregiver and patient's medical condition and the caregiver and patient's socio-demographic factors on the caregiver's CBI mean scores. The socio-demographical fixed factors included: (a) patient's and caregiver's gender, (b) patient's and caregiver's age, (c) familial relationship between patient and caregiver, (d) cohabitation/non-cohabitation, (e) availability of support for the caregiver, and (f) presence/absence of health disorders in the caregiver. These fixed factors would serve as independent variables. Patient's age was categorized as 70 or younger; between

71 and 80; and 81 or older. Caregiver's age was categorized as 50 or younger; between 51 and 60; between 61 and 70; and 71 or older. Additionally, familial relationship was identified as spouse, son/daughter, or other.

Results of the MANOVA showed no significant effects on any socio-demographical variables with the exception of those caregivers experiencing health problems (Wilks' Lambda = 0.847; $F(3,96) = 5.781$, $p < 0.001$). Univariate F-tests were significant for CBI Factor I (emotional exhaustion, impairment of caregivers' health and general functioning, $F(1,98) = 9.322$, $p = 0.003$ and CBI Factor III (patients' dependence on the caregivers' support and the time demands and restrictions caregiving demands), $F(1,98) = 10.340$, $p = 0.001$. To clarify, somatic complaints identified by the caregiver were consistent with an increase in scores on CBI Factors I and III as separate measures. These authors addressed the fact while some researchers found significant relationships between age and caregiver burden, they did not factor in the possibility that the older caregivers had greater incidences of physical health problems which may have contributed to their increase in caregiver burden [16].

With respect to the patients' cognitive impairment, DiMattei et al. [16] found no statistically significant correlation between patients' cognitive impairment and the caregivers' stress level. Patients were given an assessment using the Mini Mental State Examination (MMSE) to identify their level of cognitive functioning. The mean score at time of admission was calculated to be 17.82 (SD = +5.34; range of 6 - 24). However, the scale on which this value is based is not identified. Using the MMSE total scores and the three CBI factor mean scores, Spearman's correlation coefficient revealed no significant relationships (-0.046, 0.104, and -0.089, respectively). This suggests factors other than the level of impairment in the individual being cared for are influencing the caregivers stress level.

In evaluating the caregivers' coping strategies, the Italian version of the Coping Orientation to Problem Experienced (COPE) was used. This instrument yielded results on five factors which included social support, avoidance coping, positive attitude, focus on problem, and religion. With the five factors serving as independent variables, a step-wise multiple regression analysis was conducted to investigate the relationship between coping strategies and the burden of distress experienced by the caregiver. The three CBI scores served as dependent variables. Results of this analysis revealed avoidance coping, $F(2,106) = 14.799$, $p < 0.001$ and problem-focused coping, $F(2,106) = 5.164$, $p = 0.007$ were significant predictors of decreased distress. Conversely, personal factors of the caregiver themselves in addition to their use of adequate coping strategies is important in the caregivers' ability to overcome distress associated with the experience. Although this study addressed issues related to caring for elderly patients, the implementation of support services aimed at providing caregivers with specific coping strategies can be generalized to all caregivers including those parents of special needs children. A limitation of this study would be the fact no mention was made as to whether caregiving responsibilities were shared with others. This distinction may lead to a contrast in coping strategies as well as perception of caregiver burden. If the caregiving burden is shared, it would be possible for the primary caregiver to find respite outside the home.

According to Morris [17], a respite effect could be found in working outside the home for those mothers of children with special needs. This would essentially provide the parental caregiver with a much-needed break by buffering against the stressors associated with caregiving. To this point, there has only been minimal research and/or small non-probability samples of the empirical evidence of the respite effect, and the results have been mixed [17]. Some research has revealed working outside the home as damaging to the psychological well-being of the caregiver [18] while others revealed that working outside the home was beneficial to the caregiver by providing a buffer or respite against stressful events [19-23].

In contrast, Wong et al. [7] found when work was perceived to be stressful, awakening cortisol levels of caregiving mothers were significantly higher than noncaregiving mothers the following morning which suggests elevated levels of stress. Consequently, although work may provide some caregivers with respite away from their caregiving duties, if that work is in any way perceived to be stressful or challenging, it may simply add to the stress of caregiving as opposed to alleviating it [7].

Consequences of Caregiving

To illustrate the ramifications of caregiver stress and more specifically as it relates to parenting, the physical health of caregivers of children with health problems was assessed by Brehaut et al. [11] through a 10-year longitudinal study in an attempt to identify any significant changes in health over that time span. As identified in their review, these authors noted previous studies have shown a very diverse outcome in these assessments with some caregivers experiencing a worsening of health over time, some remaining quite stable, and others actually improving. Using a sample population of Canadian children and their caregivers, the study began in 1994 through a series of interviews when the children ranged in age from 4 to 15 years. Caregivers were interviewed and assessed on two self-reported measures of general health and depressive symptoms. Data analyses involved the chi-square (χ^2) test, the t-test, linear growth-curve models which were used to examine caregiver depression over time, and logistic growth-curve models which were used to assess general health over time. Results from this study showed caregivers of children with the most severe health concerns were less likely to report excellent or very good health themselves, $\chi^2(3) = 100.20$, $p < .001$ in addition to reporting more symptoms of depression, $F(3, 9180) = 63.96$, $p < .001$. These findings suggest not only is being a caregiver of a child with special needs stressful but both their physical and mental health tend to deteriorate with the severity of the child's illness. This conclusion is also supported by Storch et al. [24] who examined the parental experience of having a child with obsessive-compulsive disorder (OCD).

Storch et al. [24] noted in their study that family members of people with psychiatric conditions provide care for them at the expense of their own well-being. In an attempt to explore this relationship, three questions were posed. First, the researchers wanted to know if the varied domains of parental experience of having a child with OCD, correlates with parental distress and caregiver strain. Second, they wanted to know if these domains also correlate with the child's OCD symptom severity, the child's OCD-related impairment, family accommodation of symptoms, and internalizing and externalizing behavior problems. Third, they wanted to know if co-occurring child internalizing and externalizing behavior problems mediate the relations among parental experiences and parental distress [24]. Measures used in their investigation included the Children's Yale-Brown Obsessive-Compulsive Scale (CY-BOCS), Parent Experience of Chronic Illness (PECI), the Brief Symptom Inventory (BSI), the Caregiver Strain Questionnaire (CGSQ), the Family Accommodation Scale (FAS), the Child Obsessive Compulsive Impact Scale—Parent Rated (COIS-P), and the Child Behavior Checklist (CBCL).

The CY-BOCS is a clinician-rated measure designed to assess the presence/absence and severity of OCD symptoms in children [25]. This instrument was used to confirm the diagnosis of OCD in child/adolescent participants while also providing a level of severity of OCD symptoms. The PECI is a 25-item measure designed to examine parental adjustment related to caring for a chronically ill child [26]. The usefulness of this measure is it provides an indication of the extent to which the life of the caregiver has altered as a result of having to care for the child. The Brief Symptom Inventory (BSI) is a 53-item self-report inventory which reflects psychological symptom status by focusing on nine primary symptom dimensions and three global indices of distress. The Caregiver Strain Questionnaire

(CGSQ) is a 21-item self-report questionnaire used to assess the extent to which caregivers and families were affected over the previous 6 months by the demands of the child [27]. The benefit of this measure is it provides some measure of how the child with special needs can affect entire family dynamics, and not only the caregiver. The FAS is a 13-item measure (rated on a 5-point scale) that assesses 1) the degree to which family members accommodated the child's OCD symptoms over the previous 9 months (9 items), and 2) the level of distress or impairment experienced by both the family and the patient due to accommodation issues (4 items) [28]. The COIS-P is a 56-item parent rated measure that assesses the child's OCD-related impairment in several areas which include 1) child psychosocial functioning based on school activities (16 items), social activities (19 items), and home/family activities (17 items) [29]. Four additional questions were added to assess global impairment related to school, social activities, going places, and home/family activities. Lastly, the CBCL is a 118-item parent-rating scale designed to measure childhood internalizing and externalizing symptoms/behaviors over the past 6 months according to a 3-point scale with "0" referring to not true, "1" referring to true, and "2" referring to very true or often true [30]. The two composite scales of Externalizing and Internalizing problems are broken down into eight subscales consisting of: Withdrawn, Somatic Complaints, Anxious/Depressed, Social Problems, Thought Problems, Attention Problems, Delinquent Behavior, and Aggressive Behavior.

A total of 62 parent-child dyads were the sample in this study. The child and adolescent population consisted of those holding a primary diagnosis of OCD and was evenly split with 31 males and 31 females. The average age was 12.56 with a range of 6 to 20 years. The caregiver population included 53 mothers, 8 fathers, and 1 grandparent (gender not specified). Following the administration of the above-mentioned measures, a series of one-sample t-tests were calculated to conduct correlations within the study as well as to compare this data with that of a previous study conducted by Bonner et al. [26]. The Bonner et al. [26] study used a sample of 149 parents of children with terminal brain tumors to assess four factors of: Guilt and Worry (concerns for child's current and future well-being and distress about the parent's role); Emotional Resources (resources the parents have available to contend with the child's illness); Unresolved Sorrow and Anger (emotions tied to having a child with a chronic condition); and Long-term Uncertainty (concerns about the impact the illness will have on the child).

Using Spearman rank order correlation (r_s), results of the Bonner et al. [26] study revealed "Guilt and Worry" and "Unresolved Sorrow and Anger" were moderately and positively correlated with parental depressive ($r_s = .37$ and $.39$) and anxiety symptoms ($r_s = .36$ and $.32$). The Emotional Resources factor was moderately and negatively correlated with parental depressive and anxiety symptoms ($r_s = -.30$ and $-.32$). Although it was not explicitly stated, the Bonner et al. [26] study provided Storch et al. [24] with the foundation for trying to assess similar factors relative to the specific population of those caring for children with OCD.

When comparing results of the Storch et al. [24] study with those of the Bonner et al. [26] study, t-tests revealed scores for PECI Guilt and Worry factor, $t(61) = -3.80$, $p < .001$ and Unresolved Sorrow and Anger factor, $t(61) = -16.96$, $p < .001$ were significantly lower in the Storch et al. (2009) study. In contrast, the PECI Emotional Resources factor, $t(61) = 13.35$, $p < .001$ was significantly higher in the Storch et al. [24] study with no differences found for the PECI factor of Long-term Uncertainty.

Additional correlational analyses using Spearman rank order correlation were conducted on the Storch et al. [24] study alone. This involved assessing the relationships between the PECI factors and 1) parental distress; 2) caregiver strain; 3) OCD symptom severity;

4) OCD functional impairment; 5) family accommodation; and 6) child internalizing and externalizing problems. To begin, all PECE factors were analyzed against all other factors. All analyses on the PECE factor of Guilt and Worry were statistically significant with the exception of the relationship with CGSQ Externalizing Strain and CBCL Externalizing (10 of 12 factors). Significant factors paired with the PECE Guilt and Worry factor occurred with PECE Unresolved Sorrow and Anger ($r_s = .69, p < .001$); PECE Long-term Uncertainty ($r_s = .61, p < .001$); PECE Emotional Resources ($r_s = -.36, p < .01$); CGSQ Objective Strain ($r_s = .41, p < .01$); CGSQ Internalizing Strain ($r_s = .57, p < .001$); BSI Global Severity Index ($r_s = .47, p < .001$); CY-BOCS Total ($r_s = .29, p < .05$); FAS Total Score ($r_s = .40, p < .01$); COIS-P Total Score ($r_s = .31, p < .05$); and CBCL Internalizing ($r_s = .50, p < .001$).

Similarly, all analyses conducted on the PECE factor of Unresolved Sorrow and Anger were statistically significant with no exceptions (12 of 12 factors). Significant factors paired with the PECE Unresolved Sorrow and Anger factor included PECE Guilt and Worry ($r_s = .69, p < .001$); PECE Long-term Uncertainty ($r_s = .78, p < .001$); PECE Emotional Resources ($r_s = -.51, p < .001$); CGSQ Objective Strain ($r_s = .46, p < .001$); CGSQ Internalizing Strain ($r_s = .58, p < .001$); CGSQ Externalizing Strain ($r_s = .31, p < .05$); BSI Global Index ($r_s = .31, p < .05$); CY-BOCS Total ($r_s = .26, p < .05$); FAS Total Score ($r_s = .27, p < .05$); COIS-P Total Score ($r_s = .32, p < .05$); CBCL Externalizing ($r_s = .27, p < .05$); and CBCL Internalizing ($r_s = .78, p < .001$).

On the PECE factor of Long-term Uncertainty, all relationships were statistically significant with the exception of the relationship with BSI Global Severity Index (11 of 12 factors). Significant factors paired with the PECE Long-term Uncertainty factor included PECE Guilt and Worry ($r_s = .61, p < .001$); PECE Unresolved Sorrow and Anger ($r_s = .78, p < .001$); PECE Emotional Resources ($r_s = -.54, p < .001$); CGSQ Objective Strain ($r_s = .53, p < .001$); CGSQ Internalizing Strain ($r_s = .64, p < .001$); CGSQ Externalizing Strain ($r_s = .26, p < .05$); CY-BOCS Total ($r_s = .35, p < .01$); FAS Total Score ($r_s = .28, p < .05$); COIS-P Total Score ($r_s = .51, p < .05$); CBCL Externalizing ($r_s = .35, p < .01$); and CBCL Internalizing ($r_s = .30, p < .05$).

The PECE factor of Emotional Resources revealed significant negative correlations with 5 of 12 factors. Significant factors paired with the PECE Emotional Resources factor included PECE Guilt and Worry ($r_s = -.36, p < .01$); PECE Unresolved Sorrow and Anger ($r_s = -.51, p < .001$); PECE Long-term Uncertainty ($r_s = -.54, p < .001$); CGSQ Internalizing Strain ($r_s = -.45, p < .001$); and BSI Global Index ($r_s = -.28, p < .05$).

The CGSQ factors of Objective Strain, Internalizing Strain, and Externalizing Strain were also analyzed against all other factors and revealed significant results as well. On the factor of CGSQ Objective Strain, all relationships were significant with the exception of PECE factor of Emotional Resources (11 of 12 factors). Significant factors paired with the CGSQ Objective Strain factor included PECE Guilt and Worry ($r_s = .41, p < .01$); PECE Unresolved Sorrow and Anger ($r_s = .46, p < .001$); PECE Long-term Uncertainty ($r_s = .53, p < .001$); CGSQ Internalizing Strain ($r_s = .67, p < .001$); CGSQ Externalizing Strain ($r_s = .41, p < .01$); BSI Global Index ($r_s = .44, p < .01$); CY-BOCS Total ($r_s = .35, p < .01$); FAS Total Score ($r_s = .67, p < .01$); COIS-P Total Score ($r_s = .57, p < .01$); CBCL Externalizing ($r_s = .63, p < .001$); and CBCL Internalizing ($r_s = .43, p < .01$).

The CGSQ factor of Internalizing Strain revealed significant findings in all relationship factors (12 of 12). Those significant factors paired with the CGSQ Internalizing Strain factor included PECE Guilt and Worry ($r_s = .57, p < .001$); PECE Unresolved Sorrow and Anger ($r_s = .58, p < .001$); PECE Long-term Uncertainty ($r_s = .64, p < .001$); PECE Emotional Resources ($r_s = -.45, p < .001$); CGSQ Objective Strain ($r_s = .67, p < .001$); CGSQ Externalizing Strain

($r_s = .53, p < .001$); BSI Global Index ($r_s = .55, p < .01$); CY-BOCS Total ($r_s = .37, p < .01$); FAS Total Score ($r_s = .43, p < .01$); COIS-P Total Score ($r_s = .48, p < .01$); CBCL Externalizing ($r_s = .55, p < .001$); and CBCL Internalizing ($r_s = .56, p < .001$).

On the factor of CGSQ Externalizing Strain, 6 of 12 factors were significant. Those significant factors paired with the CGSQ Externalizing Strain factor included PECE Unresolved Sorrow and Anger ($r_s = .31, p < .05$); PECE Long-term Uncertainty ($r_s = .26, p < .05$); CGSQ Objective Strain ($r_s = .41, p < .01$); CGSQ Internalizing Strain ($r_s = .53, p < .001$); CBCL Externalizing ($r_s = .46, p < .001$); and CBCL Internalizing ($r_s = .29, p < .05$).

On the factor of BSI Global Severity Index, 8 of 12 factor relationships were significant. Those significant factors paired with the BSI Global Severity Index factor included PECE Guilt and Worry ($r_s = .47, p < .001$); PECE Unresolved Sorrow and Anger ($r_s = .31, p < .05$); PECE Emotional Resources ($r_s = -.28, p < .05$); CGSQ Objective Strain ($r_s = .44, p < .01$); CGSQ Internalizing Strain ($r_s = .55, p < .01$); FAS Total Score ($r_s = .38, p < .01$); COIS-P Total Score ($r_s = .34, p < .05$); and CBCL Internalizing ($r_s = .58, p < .001$).

The CY-BOCS revealed significant relationships with 9 of 12 factors. Significant factors paired with the CY-BOCS factor included PECE Guilt and Worry ($r_s = .29, p < .05$); PECE Unresolved Sorrow and Anger ($r_s = .26, p < .05$); PECE Long-term Uncertainty ($r_s = .35, p < .01$); CGSQ Objective Strain ($r_s = .35, p < .01$); CGSQ Internalizing Strain ($r_s = .37, p < .01$); FAS Total Score ($r_s = -.30, p < .05$); COIS-P Total Score ($r_s = .48, p < .01$); CBCL Externalizing ($r_s = .46, p < .001$); and CBCL Internalizing ($r_s = .41, p < .01$).

Similarly, the FAS Total Score factor showed significant relationships in 10 of 12 factors. Significant factors paired with the FAS Total Score factor included PECE Guilt and Worry ($r_s = .40, p < .01$); PECE Unresolved Sorrow and Anger ($r_s = .27, p < .05$); PECE Long-term Uncertainty ($r_s = .28, p < .05$); CGSQ Objective Strain ($r_s = .67, p < .01$); CGSQ Internalizing Strain ($r_s = .43, p < .01$); BSI Global Index ($r_s = .38, p < .01$); CY-BOCS Total ($r_s = -.30, p < .05$); COIS-P Total Score ($r_s = .52, p < .001$); CBCL Externalizing ($r_s = .44, p < .001$); and CBCL Internalizing ($r_s = .38, p < .01$).

The COIS-P factor showed significant relationships with 10 of 12 factors. Significant factors paired with the COIS-P factor included PECE Guilt and Worry ($r_s = .31, p < .05$); PECE Unresolved Sorrow and Anger ($r_s = .32, p < .05$); PECE Long-term Uncertainty ($r_s = .51, p < .05$); CGSQ Objective Strain ($r_s = .57, p < .01$); CGSQ Internalizing Strain ($r_s = .48, p < .01$); BSI Global Index ($r_s = .34, p < .05$); CY-BOCS Total ($r_s = .48, p < .01$); FAS Total Score ($r_s = .52, p < .001$); CBCL Externalizing ($r_s = .47, p < .001$); and CBCL Internalizing ($r_s = .55, p < .001$).

The CBCL Externalizing factor was statistically significant among 9 of 12 factors. Significant factors paired with the CBCL Externalizing factor included PECE Unresolved Sorrow and Anger ($r_s = .27, p < .05$); PECE Long-term Uncertainty ($r_s = .35, p < .01$); CGSQ Objective Strain ($r_s = .63, p < .001$); CGSQ Internalizing Strain ($r_s = .55, p < .001$); CGSQ Externalizing Strain ($r_s = .46, p < .001$); CY-BOCS Total ($r_s = .46, p < .001$); FAS Total Score ($r_s = .44, p < .001$); COIS-P Total Score ($r_s = .47, p < .001$); and CBCL Internalizing ($r_s = .52, p < .001$).

The final factor analyzed was the CBCL Internalizing factor which was statistically significant among 11 of 12 factors. Significant factors paired with the CBCL Internalizing factor included PECE Guilt and Worry ($r_s = .50, p < .001$); PECE Unresolved Sorrow and Anger ($r_s = .30, p < .05$); PECE Long-term Uncertainty ($r_s = .30, p < .05$); CGSQ Objective Strain ($r_s = .43, p < .01$); CGSQ Internalizing Strain ($r_s = .56, p < .001$); CGSQ Externalizing Strain ($r_s = .29, p < .05$); BSI Global Index ($r_s = .58, p < .001$); CY-BOCS Total ($r_s = .41, p < .01$); FAS Total Score ($r_s = .38, p < .01$); COIS-P Total Score ($r_s = .55, p < .001$); and CBCL Externalizing ($r_s = .52, p < .001$).

When considering the aforementioned results and their relevance to the current study, several conclusions can be drawn. First, emotional responses of guilt, worry, anger, and sorrow are consistently present among caregivers that escalate the amount of stress, which is detrimental to caregivers' well-being. Second, the demands of caregiving explicitly affect these emotional responses as there is often little time for respite. Caregiving is a long-term practice that requires great sacrifice, with what may be perceived as little reward, as the condition of the afflicted individual is often unchanged (i.e., chronic strain). Third, as the severity of the child's illness increases, it is probable there will be an increase in the amount of stress. With increased amounts of stress, it is logical to infer caregiver quality of life would falter.

Additional analyses of the Storch et al. [24] study included the Baron and Kenny mediation analyses. Initially, three relationships were analyzed to assess their ability to predict parental or caregiver distress. These relationships included 1) parental experience of Guilt and Worry with Parental Distress; 2) parental experience of Sorrow and Anger with Parental Distress; and 3) parental experience of Emotional Resources with Parental Distress. The first mediation analysis involved internalizing problems as a mediator of the parental experience of Guilt and Worry and Parental Distress. This analysis revealed the CBCL Internalizing Scale ($B = .46, p < .001$) mediated the relationship between the PEGI Guilt and Worry factor ($B = .24, ns$) and the BSI total score, $F(2, 55) = 16.76, p < .001$ and accounted for 38% of the variance in the outcome measure of parental distress mediated by the severity of internalizing problems of the child as perceived by the caregiver.

The second mediation analysis involved internalizing problems as a mediator of the parental experience of Sorrow and Anger and Parental Distress. This analysis revealed the CBCL Internalizing Scale ($B = .54, p < .001$) mediated the relationship between the PEGI Sorrow and Anger factor ($B = .13, ns$) and the BSI total score, $F(2, 55) = 14.74, p < .001$ and accounted for 35% of the variance in the outcome measure of parental distress mediated by the severity of internalizing problems of the child as perceived by the caregiver.

The third mediation analysis involved internalizing problems as a mediator of the parental experience of Emotional Resources and Parental Distress. This analysis revealed the CBCL Internalizing Scale ($B = .54, p < .001$) mediated the relationship between the PEGI Emotional Resources factor ($B = -.14, ns$) and the BSI total score, $F(2, 55) = 14.99, p < .001$ and accounted for 35% of the variance in the outcome measure of parental distress mediated by the severity of internalizing problems of the child as perceived by the caregiver.

Results of the aforementioned mediation analyses help in identifying specific relationships as well as mediators that explain the "why" or the "how" of those relationships. More specifically, scores on the CBCL Internalizing Scale were found to mediate relationships between caregiver stress and "Guilt and Worry," "Sorrow and Anger," and "Emotional Resources." These findings suggest specific internalizing behaviors of the child influence the emotional responses and resources of the parent thereby influencing the parent's level of distress. Additional findings suggest parents of children with OCD are considerably distressed about their child's condition with negative experiences being directly related to OCD symptom severity and impairment. These findings are consistent with other research on caregiver stress indicating stress and stress-related illnesses are likely to be prevalent in parents and caregivers of children with mentally or physically handicapped conditions and the child's level of activity or impairment greatly affects the caregiver's ability to function which in turn, negatively affects the caregiver's quality of life.

When a parent is challenged with having to care for a mentally or physically handicapped child, their ability to maintain a sense of wellbeing is vital in their ability to function and provide that child

with adequate care. With increases in the number of diagnosed cases of autism spectrum disorders (ASD) [31], caregivers of these children are likely to add to the vulnerable population of caregivers experiencing great amounts of stress related to their child's condition. The CDC [31] estimates that ASD occurs in 1 of every 68 children. Such alarming numbers give rise to the probability some caregivers may experience difficulty in coping with these circumstances as they relate to their individual child.

To further evaluate the impact of caregiver stress and particularly as it relates to those caring for children with ASD, Hayes and Watson [32] conducted two meta-analyses of studies comparing the experiences of parents of children ASD and those without ASD. Additionally, the parents of those children without ASD included children who were either typically developing or experiencing other disabilities such as Down syndrome or cerebral palsy. Utilizing a total of 15 research articles from years 1989 to 2012 (comprised of unpublished dissertations as well as published works) assessing parenting/caregiver stress, these authors concluded there is significantly greater stress among parents of ASD children than those parents of typically developing children.

Using the same 15 studies, a second meta-analysis reinforced that parenting stress was significantly greater among parents of children with ASD when compared to the stress levels of parents of children with other disabilities [32]. These findings suggest caring for those with ASD has its own set of unique demands or challenges that set it apart from other conditions. Though the review does not explain why or how these differences may occur, the existence of mediating and/or moderating factors is apparent.

In summary, caregiver stress will continue to persist as long as physical and mental conditions are present requiring the immediate and constant attention of professionals and of loved ones who are tasked with their care. Therefore, it is imperative to consider any and all strategies which may provide these caregivers with tools necessary to not only help them in their quest to help others, but also to help themselves as well and provide a positive influence on the caregiver's quality of life.

Role of Other Family Members

Given the consequences of stress, the identification of vulnerable populations is necessary in reducing severity of stress and raising their quality of life. According to the vulnerability model proposed by Carr [33], certain groups or populations are susceptible to disease, morbidity, and premature death due to a lack of resources. Originally, Flaskerud and Winslow [34] conceptualized women and children, ethnic people of color, immigrants, gay men and lesbians, the homeless, and the elderly (as cited in [33]). The suggestion here is caregivers of those with special needs should be a part of this population due to constant exposure to the stressful demands of caregiving thereby making them more susceptible to the illness and detriments associated with chronic stress identified previously. As such, one must address or account for the entire family dynamic in which the ill family member dwells. Because caregiving often involves chronic illness, the challenges and stress experienced by family members can include being an abusive target of the family member who is ill, diminished social and/or leisure time, and the possibility of having to leave employment or reduce employment time to care for the afflicted [35]. When these stressors are present, the support of other family members becomes extremely beneficial.

Depending on the specific needs of the child, siblings and other family members can come to aid the primary caregiver in several different ways [36]. This may include giving the caregiver a break or respite from caregiving duties, assisting with certain tasks, as well as simply providing emotional support. However, when family environments are addressed in the current literature, the focus is primarily placed on the extent the special needs person impacts his/her

family members' lives [37,38]. Researchers found positive influences of other family members with respect to how they buffer caregiver stress [36, 39, 40, 41]. Although these studies did not focus on the mechanism through which caregiver stress is minimized, Sawyer et al. [38] examined time demands associated with caring for children with autism and how this affects the caregiver mothers' mental health. Results of their study showed: 1) a high rate of mental health problems are associated with time demands; 2) mothers having more social support also reported fewer mental health problems; 3) mothers spent on an average 6 or more hours per day caring for their children; and 4) mothers feeling pressured by the demands had more psychological impairment than those not feeling pressured. Thus, perceived time pressure contributes to mental health problems more than the actual number of hours spent caregiving. Because perception varies from one individual to the next, what one person may perceive to be threatening or overwhelming may be perceived as merely challenging or typical of the situation by others.

To further address family dynamics associated with caring for family members with special needs, Smith and Elder [42] conducted a literature review of siblings, parental characteristics, and relationships within the family with respect to autism spectrum disorder spanning over the last ten years. In an attempt to close the gap in previous research, these researchers suggested that more focus should be placed on assessing typically developing siblings of those children with special needs to identify those at risk for future issues or problems with behavior and adjustment. This conclusion was based on results showing siblings are influenced by the circumstances of their families and are therefore impacted by biological, psychological, sociological, and ecological factors. However, the impact these typically developing children have on their caregiving parents was not addressed. Their study was restricted to four areas identified as parental characteristics, sibling behaviors, sibling relationships, and sibling adaptation. In addition to conditions such as cerebral palsy, attention-deficit hyperactivity disorder and others, siblings of those with autism spectrum disorder continue to be an understudied population [42]. According to Neely-Barnes and Graff [43], a major reason for the lack of research among this population is the inability to recruit them as few organizations and support groups address their needs.

Role of Parenthood Perception

Generally speaking, perception of parenthood pertains to how a parent views his or her situation based on certain factors deemed as essential to the parenting concept. This may include factors such as the parent/child dynamic, spousal relationships, and how they view their ability to take care of their children's needs. More specifically and according to the Parenting Satisfaction Scale (PSS), perception of parenthood for the current study pertains to parents' attitudes toward parenting based on (a) Satisfaction with Spouse/Ex-Spouse Parenting Performance, (b) Satisfaction with the Parent-Child Relationship, and (c) Satisfaction with Parenting Performance [44]. In order to establish connections between perception, stress, and quality of life, it is necessary to address perceptions as beliefs which often stem from one's personal experience and "self" view [45].

The context for perception of parenthood stems from the question of whether typically developing children could stimulate a more positive perception of parenthood while concurrently improving quality of life among parental caregivers rearing a child with special needs. Although the source of stress can originate from many avenues, exactly why or how it is some individuals can experience similar stressors, and yet have completely different outcomes of well-being is of great importance. Looking specifically at caregiver quality of life among the population of parents caring for children with special needs, very little attention has been paid to the role of the typically developing siblings of the children with special needs and specifically how they may factor into the well-being of their caregiver parents.

How an individual perceives parenthood may have its origin from a variety of sources which could include personal experience, perceptions of the self, media, or any other entity providing exposure to this specific role. One such source could be how an individual perceives parenthood in general. This would include the scenario that parenthood can generate both feelings of joy as well as stress with the only difference being the person having the experience. The rationale behind this reasoning is based on the relationship between self-efficacy and perception of parenthood [46,47]. Accordingly, it is possible for two individuals to encounter the same or similar situation although they may have completely different views or perceptions of that experience. A common cliché referring to this phenomenon is the statement "beauty is in the eye of the beholder." It is not unusual for individuals to perceive things differently. However, the question is, "what are the factors that influence those differences?"

When considering individual perceptions of parenthood, the influence of that viewpoint is contingent on many variables [48]. For example, perceptions can be influenced by simply having a child or not being able to conceive a child [49]. In this context, Umberson et al. [49] suggested varied roles of parenting, which include step-parenting, parenting of grandchildren, and even childlessness, have a significant impact on individuals throughout the life course. Additional findings suggest when children are young, they tend to be more of a burden than an asset due to the attention and amount of time they demand but when these children become adults, they tend to have a more positive effect on the well-being of their parents [49]. Other variables influencing the well-being of parents include cohabiting or marital satisfaction, along with the addition of a baby, although it could depend on the caregivers' perception of parenthood [50, 51].

In contrast to studies showing an increase in well-being associated with parenthood, others have shown a decrease in well-being [52, 53]. In a longitudinal study conducted by Dyrdal et al. [52], findings revealed although life satisfaction increased during pregnancy, both life satisfaction and relationship satisfaction decreased after the birth of the child. Similar results were found by Hoffenaar et al. [53] who reported no pre- and postnatal differences between life satisfaction, depression, and anxiety in a group of 19 first-time mothers regardless of the health status of the child. As such, having typically developing children may increase, decrease, or have no bearing on quality of life depending on the parent's perception of parenthood.

When considering the above-mentioned factors of how some individuals perceive parenthood, their role in the context of family stress is well documented. In a study conducted by Dimpka and Wilcox [54], perceptions of married couples as related to family stress were assessed among a population of 200 married couples using the Family Stress Questionnaire (FSQ) designed by the researchers. This instrument was used to measure the couples' perception of family stress and findings revealed males and females varied significantly in their perceptions. More specifically, women were much more prone to family stress which was likely due to their significant roles within the home. The relevance of these findings to the current research is with many women having caregiving responsibilities, the added stressor of having to care for a child with special needs would simply add to an already perceived stressful situation.

Further, in a longitudinal study conducted by Tremblay and Pierce [47], the perceptions of parenthood were measured based on how mothers perceived the involvement of fathers, how these same men perceived themselves as fathers as well as how they perceived their relationship with the mothers. Both mother and father were examined at three specific time points in the first 18 months, following the birth of the couple's first child. There was a total of 183 heterosexual couples who completed self-report questionnaires which were taken at the child's age of two months, five months, and 18 months. Assessments included measures of fathers' perception of the

importance of their parental identity, their parental self-efficacy, and their marital satisfaction. Assessments were also made of the mothers' perceptions of the quality and quantity of paternal involvement in childcare. Using repeated measures ANOVAs, results showed only a slight difference between the mean levels of each of the five measures over the first two assessment periods of two and five months respectively. However, significant changes were found in three of the five measures between the last two assessment periods of five months and 18 months, respectively. There was a significant increase in father's parental self-efficacy and mother's perceptions of the quantity of paternal involvement in childcare between five and 18 months respectively, $F(1, 156) = 40.23, p < .001$, partial $\eta^2 = .21$. These authors concluded new mothers and fathers influence each other's perceptions when it comes to fatherhood. In short, how fathers perceive themselves is based in part on their self-efficacy as well as how their partners view them as well. These findings suggest perceptions of parenthood are susceptible to change.

Although the existing literature has shown individual perceptions of stress can dramatically alter one's quality of life depending on how circumstances are perceived, an additional area of concern is caregiver perception based on the self-stigma associated with having a child with a disorder. Like many others, Hasson-Ohayon et al. [55] agree parenting children with psychiatric disorders has its challenges and is associated with caregiver stress and burden. However, their contribution stems from their research in the area of self-stigma which they refer to as the process by which a person with a mental disorder loses a previously held or hoped for identity of the self and instead adopts a more stigmatizing view often held by others in the community [55]. For example, if the community views the individual as dangerous then he or she will adopt the same view or self-stigma. The relevance of this to the caregiver is the same self-stigma has been reported in family members of the afflicted individual sensibly due to the perceptions the family is merely an extension of the individual with the disorder as well as the source [55]. Therefore, if the child has problems, there must be something wrong with the family or caregiver as well.

Because expectations and what is deemed as successful or positive is very much dependent on the individual, there are differences in terms of how success and parenthood are perceived [48]. Depending on their perception of parenthood, having typically developing children may either increase or decrease the quality of life of the caregiving parent. This relationship may be explained by the value the caregiving parent places on the typically developing child. For instance, if a parent has a positive perception of parenthood, typically developing children may enhance quality of life. However, if the parent has a poor or low perception of parenthood, having a typically developing child may actually decrease the parent's quality of life.

Quality of Life

Quality of life is often used synonymously with life satisfaction, happiness, mental well-being, and health status and is often assessed as being either high or low [56, 57]. Because of the many factors associated with one's quality of life, the multidimensional nature of the concept makes it difficult to define. As such, Glozman [58], Murrell [59], and Phillips [60] view quality of life as a culmination of the following: (1) an outcome of health care and rehabilitation; (2) a health status and a sign of functional ability, disease progression or regression; (3) a manifestation of social circumstance and external conditions; and (4) a subjective internal construct of self-evaluation and psychological well-being not corresponding closely to external conditions (as cited in [61]). When assessing quality of life, it is often measured in terms of physical symptoms manifested by way of mental and/or physical stressors giving rise to the term health-related quality of life [12, 62]. Although its origin dates back to the 1990s, as late as 2004 quality of life was considered a new concept [61].

According to Glozman [61], families are the most valuable yet

vulnerable resources for their disabled family member as caregiving represents one situation in which chronic stress can develop. This level of stress in turn leads to a decrease in caregiver's well-being or quality of life [63]. Many caregivers are forced to make sacrifices to their professional and social life as a necessity to make themselves available to cater to the needs of their loved one. This significant burden of caregiving threatens the emotional and physical well-being of the caregiver [61].

When assessing quality of life as an outcome or consequence, much of the current literature focuses on this concept as it applies to those individuals being cared for as a result of affliction with a specific illness or chronic condition. Unfortunately, research regarding the quality of life of parental caregivers of children with special needs is scarce and in greater need of attention, particularly with the increasing numbers of children with chronic conditions such as autism spectrum disorders [31]. In a study conducted by Lee et al. [36], health-related quality of life was assessed in parents of children with high-functioning autism spectrum disorders (ASDs) and compared to the health-related quality of life of parents of children without any disabilities. More specifically, the researchers wanted to (1) know if parents of high-functioning ASDs reported lower health-related quality of life than those parents of children with no known disabilities, and (2) identify specific relationships between demographic and psychosocial variables and health-related quality of life. Using a sample of 135 parents, comparative groups included 89 parents of children with high functioning ASD and 46 parents of children with no known disabilities. The measures used in this study included the (1) demographic form, (2) Family Crisis-Oriented Personal Evaluation, (3) Family Inventory of Resources for Management, (4) Parenting Stress Inventory-Short Form, (5) Perceived Severity of Child's Condition and (6) MOS 36-Item Short-Form Health Survey (Version 1.0).

The demographic form included items requesting parent's gender, age, marital status, ethnicity, education, number of children, and household income. The Family Crisis-Oriented Personal Evaluation (FCOPE) [64] is a 30-item self-report instrument that measures coping by way of problem-solving attitudes and behaviors used by families in response to problems or difficulties. All items are scored on a 5-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). This instrument is broken down into five subscales of coping mechanisms used in times of stress which included (1) Acquiring Social Support, (2) Reframing, (3) Seeking Spiritual Support, (4) Mobilizing Family to Acquire and Accept Help, and (5) Passive Appraisal. Subscales are added to produce a total score with higher scores indicating a greater use of coping mechanisms.

The Family Inventory of Resources for Management [65] is a 69-item self-report instrument used to measure the social, psychological, community, and financial resources families perceive to be available to them in managing family life. Rated on a 4-point Likert-type scale ranging from 0 (not at all) to 3 (very well), this instrument is broken down into four subscales which include (1) Family Strengths I: Esteem and Communication, (2) Family Strengths II: Mastery and Health, (3) Extended Family Social Support, and (4) Financial Well-being. Subscales are summed to yield a total score with higher scores indicating a greater belief in available resources.

The Parenting Stress Inventory-Short Form (PSI) [66] is a 36-item self-report instrument designed to measure perceived levels of stress associated with parenting. All items are scored on a 5-point Likert-type scale ranging from 5 (strongly agree) to 1 (strongly disagree) and are broken down into three subscales identified as (1) Parental Distress, (2) Parent-Child Dysfunctional Interaction, and (3) Difficult Child. Scores on subscales are added to yield a total score with the higher score being indicative of greater stress.

The Perceived Severity of Child's Condition is an assessment developed by the researchers for the purpose of measuring parent's

perceived severity of the child's disability. Measures are taken on a 6-point Likert-type scale ranging from 0 (*not severe*) to 5 (*very severe*). Validity measures of this instrument were based on correlational results of two unpublished pilot studies in which the Perceived Severity of Child's condition was assessed with the Behavioral Symptoms Index and the Parenting Rating Scales of the Behavioral Assessment System for Children- Second Edition [67]. Results of the first pilot study which involved a sample of 59 children with high functioning ASDs showed significant correlations of .64 ($p < .001$) and .61 ($p < .001$) respectively. Similarly, the second pilot study which involved a sample of 36 children (18 with high functioning ASD and 18 typically developing children) revealed significant correlations of .90 ($p < .001$) and .81 ($p < .001$). These results provide evidence of the concurrent and discriminate validity of the severity rating scale [36].

The MOS 36-Item Short-Form Health Survey (Version 1.0) [68] is a 36 item self-report instrument used to measure health-related quality of life. This instrument yields two higher-order summary scores identified as the Physical Health Summary Score and the Mental Health Summary Score. The Physical Health Summary Score is based on subscales of (1) Physical Functioning, (2) Role Limitations Due to Physical Health, (3) Pain, and (4) Energy/Fatigue. The Mental Health Summary Score is based on subscales of (1) Role Limitations Due to Emotional Problems, (2) Energy/Fatigue, (3) Emotional Well-Being, and (4) Social Functioning. Indicators of the Likert-Type responses were not specified but high scores are indicative of higher health-related quality of life.

Using the above-mentioned measures, Lee et al. [36] performed independent samples t-tests to assess differences between the parents of high functioning ASDs and parents of children with no known disabilities. The variables assessed in these analyses included physical health quality of life, mental health quality of life, parenting stress, coping, and family resources. Additionally, hierarchical regression analyses were performed to assess the relationships of psychosocial variables and health-related quality of life among the parents of high functioning ASDs. With respect to the t-tests, significant differences were found in all areas between the two groups and included the following results: (1) Physical Health quality of life, $t = -2.48$, $p < .05$; (2) Mental Health quality of life, $t = -2.90$, $p < .05$; (3) Parenting Stress (PSI), $t = 8.57$, $p < .001$; (4) Coping (FCOPE), $t = -1.84$, $p < .05$; and (5) Family Resources (FIRM), $t = -2.90$, $p < .05$. Findings on the difference between Mental and Physical Health suggest parents of children with high functioning ASDs have a significantly lower quality of life when compared to those parents of typically developing children whereas the findings from the psychosocial variables of stress, coping, and resources suggest parents of children with high functioning ASDs experience higher levels of stress, lower levels of adaptive coping, and fewer resources [36]. Implications of these findings are clear in identifying the relationships between the parenting of children with special needs, parenting stress, and quality of life.

Looking specifically at the parents of the high functioning ASDs, Lee et al. [36] conducted hierarchical regression analyses to examine the relationships between the demographic and psychosocial variables with health-related quality of life (physical and mental). Looking first at the physical health quality of life as the dependent variable, step one of the regression analyses involved entering all five demographic (predictor) variables of parent age, parent education, family income, number of children in the family, and perceived severity of the child's disability. When considered together, all demographic variables were significant in predicting physical health-related quality of life in parents of high functioning ASDs, $F(5,53) = 2.546$, $p = .039$. Individually, significant relationships were found between family income and caregiver physical health-related quality of life ($t = 2.947$, $p = .005$), and number of children in the home

and caregiver physical health-related quality of life ($t = 2.114$, $p = .039$). These findings suggest higher income and more children in the family are associated with better physical health quality of life [36]. Step two of the regression analyses involved entering the three psychosocial (predictor) variables of stress, resources, and coping while controlling for the five demographic variables. Collectively, all psychosocial variables were significant in predicting physical health-related quality of life, $F(8,50) = 2.77$, $p = .013$ after controlling for the five demographic variables. Individually, the only significant relationship occurred between stress and caregiver physical health-related quality of life ($t = -2.344$, $p = .023$). This finding suggests stress is negatively associated with physical health quality of life [36].

Next, hierarchical regression was used again to investigate the relationships between the aforementioned demographic and psychosocial predictor variables with mental health quality of life as the dependent variable. Step one of the regression analyses involved entering all five demographic (predictor) variables. When considered together, all demographic variables were significant in predicting mental health-related quality of life in parents of high functioning ASDs, $F(5,53) = 3.197$, $p = .014$. Individually, only family income ($t = 3.413$, $p = .001$) was significantly associated with better mental health quality of life. Step two of the regression analyses involved entering the three psychosocial (predictor) variables and controlling for the five demographic variables. Collectively, all psychosocial variables were significant in predicting mental health-related quality of life, $F(3,50) = 4.149$, $p = .011$ after controlling for the five demographic variables. Individually, the only significant relationship occurred between stress and mental health quality of life ($t = -2.492$, $p = .016$). This finding suggests stress is negatively associated with mental health quality of life [36].

To summarize, results of the Lee et al. [36] study showed significant differences in the quality of life between the parents of high functioning ASDs and the parents of typically developing children. Also, among the high functioning ASD sample, significant relationships were established between health-related quality of life and the demographic (parent age, parent education, family income, number of children in the family, and the level of severity of the child with the disability), and the psychosocial (stress, resources, and coping) variables. Good physical and mental health are essential to caregiver quality of life. However, these attributes often decline or worsen as a result of (1) a lack of time to recuperate from providing basic and medical care for the disabled child, (2) lack of control over the situation, and (3) decreased energy level [36, 38, 40]. The presence of these life situations leads to an increase in stress which in turn leads to a decrease in quality of life.

Factors Influencing Caregivers' Quality of Life

Due to individual differences, factors influencing quality of life can be as varied as the individuals themselves. Consequently, it would be virtually impossible to identify all factors influencing quality of life among caregivers for this very same reason. However, prior research has looked at factors such as income or family resources, community resource utilization, and marital status of the caregiver as additional factors known to influence caregiver quality of life. Although the current study does not address these factors as variables, their inclusion in this review is pertinent to demonstrate how other factors may impact caregiver quality of life.

In many families of children with special needs, a significant source of stress is a lack of financial resources [69]. When considering Hill's ABC-X model and family stress theory, income falls in the category of family resources expressed as "B." As stated previously, these resources include having sufficient financial means in addition to good physical and psychological health, family cohesiveness, and the use of formal services such as home care and community-based

social services [12]. Researchers Rothwell and Han [69] note economic resources play a vital role in family functioning and with the current economic recession, those with low incomes are subject to an even greater strain. Family functioning can also be influenced by additional stressors such as neighborhood conditions due to low-income housing (which does not always include favorable conditions), bureaucratic difficulties, violent intimate relationships, inability to meet the needs of their children, and in some instances, incarceration [70].

Aside from financial support which is viewed as a personal resource, external social support or respite care has also been seen to be beneficial [17, 71]. As its name indicates, special needs children often require special services or resources beyond the scope of ordinary care. A plethora of literature concerning caregiver quality of life focuses on the availability of resources and utilization of services (which are not always feasible) as expenditures can sometimes be well above and outside the caregivers' financial means [72,73]. Psychological stress is more likely to occur if the child requires considerable social, financial, and health care resources [74]. Stated differently, low socioeconomic status and the absence of social support are associated with maternal mental health problems such as depression and anxiety. When specialized services and resources are utilized, benefits include providing better coping skills, knowledge about their child's condition, and skill in caring for their child [75,76]. Some parents may also find things to be less stressful when their children begin school by affording parents with an opportunity for respite and rejuvenation.

Individuals who take advantage of available resources report lower levels of stress although usage is largely determined by the level or severity of client needs [77, 78]. Parental caregivers of children having spina bifida report having to constantly set up appointments, take children for whatever care is available, toileting, locomotion, and other daily activities [13]. Caregivers of children with Smith Magenis Syndrome (SMS) report similar demands. A disorder characterized by intellectual disability, speech delay, decreased pain sensitivity, sleep disturbances, hyperactivity, mood instability, and self-injury, SMS caregivers often encounter difficulties in maintaining a high level of well-being [79].

Although service utilization is important in helping families cope with their circumstances, the caregivers' perception of available resources is likely to dictate the usage of such services as well. Researchers Carborne, Behl, Azor, and Murphy [80] reported parents of autism spectrum disorder children often perceive physicians as not acting early enough when it came to developmental concerns about their children and care is less comprehensive, coordinated and family-centered. This perception could possibly lead to a lack of confidence and trust in treatment resulting in little to no usage of available resources. These perceptions and concerns must be addressed, as the occurrence of anger and stress are likely to increase especially when the severity of the child's illness dictates more attention [81].

Another issue related to service utilization is the financial status of the family. Poverty or lack of financial resources often limits the ability to meet the needs of children with disabilities [82]. Financially affluent families were more likely to take advantage of such resources and had children who were less likely to have cognitive and language difficulties. These families were also more likely to seek out additional resources if they felt the need. While these findings reflect the added benefits of having financial resources as a gateway to additional services such as those provided by community or federally funded agencies, they also suggest the two are exclusive of one another and when combined, can create a better outcome for the family. However, some families sadly may not qualify for certain government programs that may make their living situations a lot more sustainable. Because income may provide access to resources, or reduce stress in other ways, it is likely to affect caregiver stress

when dealing with a child with special needs, which in turn is likely to impact caregiver quality of life. Recent research conducted by Lindley and Mark [73] confirmed this relationship in their findings which revealed those who do not have sufficient resources perceive health care expenses as a burden which leads to a negative impact on the caregivers' quality of life.

In summary, the utilization of community resources as well as the ability to afford such services is essential. When services are available but not utilized, negative consequences of unnecessary stress could result when it likely could be avoided. Likewise, if services are available, but costs are beyond what the family can afford, the same negative consequences may result. Depending upon the child's condition, treatment plans of how to manage that condition are standard. It is imperative health care providers educate parents so they can take full advantage of all resources available to them.

With respect to marital status, the benefits of a spouse are similar to what could be found with any other family member present in the home. For example, the spouse can be there to provide moral support and respite to the primary caregiver when needed [12]. However, because of the time demands often associated with the care of those in need, the obligation may actually put a strain on the marriage by taking away from quality time that would otherwise be designated for the couple. According to Hartley et al. [83], the rate of divorce of parents of children with autism spectrum disorder is higher when compared to those parents who do not have children with any known disabilities (23.5% to 13.8%). Further, these researchers found as the child with special needs increased in age, the divorce rate continued to remain high, whereas the comparison group had a decline in rates over the same time-frame of their non-disabled children. These analyses suggest marriage can be very beneficial in providing primary caregivers with support thereby reducing the level of stress. However, if the marital relationship becomes negatively impacted by the caregiving, an increase in stress may result along with the possibility of divorce as the marital relationship becomes strained.

Summary

The literature review provides a foundation, identifies gaps, and provides a guide for research assessing perception of parenthood as a moderator variable between typically developing children and parental caregiver quality of life. Caregiver stress is an unfortunate by-product of those caregiving for others who are unable to care for themselves and it is in this context the lives of these individuals are impacted. As the stress abounds, it begins to take a toll on individuals' physical health by making them more susceptible to cardiovascular illnesses [4, 10]. One way to counter the effects of caregiver stress is to utilize any and all available resources. For example, when specialized services and resources are utilized, they provide caregivers with support making them better able to cope and more knowledgeable of their child's condition [75, 76]; a point consistent with other findings showing those individuals who take advantage of available resources have lower levels of stress [77, 78]. Although the benefits of such usage are well-documented, the willingness of caregivers to take advantage of such services remains an issue. These factors include the perception of the availability of resources [80], and the fact poverty or lack of financial means can serve as a barrier to accessing necessary services [82].

With respect to the influence of other family members, a second point shows that family members can be positive influences in reducing caregiver stress [36,39-41]. However, as the current research has identified, exactly how this occurs is unknown [36]. Further, Smith and Elder [42] identified the role of siblings as an understudied population. Although there has been some research in terms of siblings being at risk for future problems [43, 42], nothing has been done to address how this population may be an asset to their parent's well-being. This lack of research may be due to additional children being viewed as a liability by adding to the caregiver's

workload. Accordingly, Goldstein and Ross [84] looked at the perceived burden of children in assessing the psychological distress of mothers and found for younger mothers, the level of burden increases with each additional child whereas no such increase occurs with older mothers. Although these findings represent mothers of children with no known disabilities, the increase of stress is highly probable when children with special needs are included. With time demands (i.e., amount of time spent caring for the child in a 24 hour period and the perceived pressure of time) being such a major factor in caregiving [38] the fact some typically developing children can assist their parents is vital to the well-being of the caregiver. However, the value of these typically developing children in reducing caregiver stress and raising quality of life is unknown beyond simply helping with caregiving responsibilities. Because typically developing children are known to impact their caregiver parents either negatively or positively, there is likely to be a third variable moderating this relationship. Future research should address this possibility by assessing whether perception of parenthood serves as a moderator of the relationship between having typically developing children and parental caregiver quality of life.

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