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Abir K. Bekhet Marquette University, abir.bekhet@marquette.edu

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Self-Assessed Health in Caregivers of Persons with Autism Spectrum Disorder: Associations with Depressive Symptoms, Positive Cognitions, Resourcefulness, and Well-Being

Abir K. Bekhet

Marquette University College of Nursing, Milwaukee, Wisconsin

Abstract

Purpose

Caregiving for children with autism spectrum disorder (ASD) can affect family caregivers' self-assessed health. The purpose of this study was to determine whether depressive symptoms, positive cognitions, resourcefulness, and well-being will differ significantly among those who rated their health as fair, good, or excellent.

Design and Methods

This study is a secondary analysis of 109 ASD caregivers who were recruited from the Interactive ASD Network.

Findings

Depression was significantly lower among those who rated their health as excellent than among those who rated their health as fair. Positive cognitions, resourcefulness, and well-being were significantly higher among those who rated their health as excellent than among those who rated their health as fair.

Practice Implications

Interventions to enhance caregivers' positive cognitions, resourcefulness, and well-being are recommended.

The number of American children diagnosed with autism spectrum disorder (ASD) has risen dramatically in recent years. The estimated overall increase is approximately 25% since 2006, and the number is now nearly double the number reported in 2002. One in 88 persons is currently affected with ASD (Begley, 2012; Centers for Disease Control and Prevention, 2008). ASD is a complex developmental disability that substantially affects a person's communication and social interactions. Persons with ASD can be aggressive, anxious, overactive, and self-injurious (Hoffman et al., 2008; Matson & Fodstad, 2009). ASD symptoms emerge before age 3 (American Psychiatric Association [APA], 2000), and caregiving for children with ASD is demanding and can affect family caregivers' physical and psychological well-being (Altiere & Von Kluge, 2009; Baker, Blacher, & Olsson, 2005; Benson, Karlof, & Siperstein, 2008; Gray, 2006; Phetrasuwan & Miles, 2009).

Previous research has indicated that caregivers report depressive symptoms associated with the burden of providing care to persons with ASD (Benson & Karlof, 2009; Carter, Martinez-Pedraza, & Gray, 2009; Ekas, Lickenbrock, & Whitman, 2010), and recent research has shown that children and adolescents with ASD themselves may experience depression (Strang et al., 2012), which can in turn increase caregivers' depression (Haeffel & Hames, 2013). Parents of persons with ASD have been shown to be at higher risk for developing depression than parents of normally developed children (Benson, 2006). Previous research has also shown that 33% of mothers and 17% of fathers of persons with ASD are clinically depressed (Davis & Carter, 2008; Karst & Van Hecke, 2012). One study found that more than one third of mothers of toddlers and adolescents with ASD had higher scores on a depression scale than clinical cutoff scores (Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008).

Previous research has also found that parents of children with ASD reported higher levels of fatigue (Smith et al., 2010) and greater deterioration in physical health than parents of typically developing children and children with intellectual disabilities (Allik, Larsson, & Smedje, 2006; Mugno, Ruta, D'Arrigo, & Mazzone, 2007). One study found that parents of persons with ASD reported significantly lower self-perceived health and more deterioration in health in the last year than a control group (p < .001). The study also found more psychological disorders than in the control group (11% vs. 4.3%; Benjak, Mavrinac, & Šimetin, 2009). However, no previous research has investigated the relationship

between self-assessed health and depression or between self-assessed health and protective factors in caregivers of persons with ASD as proposed in this study.

Resilience involves a dynamic process of balancing risk and protective factors in the face of challenges (Van Breda, 2001). Protective factors can increase resilience by minimizing the effects of risk factors, thereby increasing well-being (Bekhet, Johnson, & Zauszniewski, 2012). One protective factor examined in this study was positive cognitions, which refer to positive thinking patterns that help caregivers to carry on with their daily activities and help them to promote their mental health (Zauszniewski, McDonald, Krafcik, & Chung, 2002). Previous research has found a negative association between positive cognitions and depression severity in diabetic women (Zauszniewski et al., 2002). Also, research has found that positive cognitions helped older adults who relocated to retirement communities cope with the challenges of relocation and perceive their relocation experiences more positively (Bekhet, Zauszniewski, & Wykle, 2008).

Another protective factor examined here was resourcefulness, which is a collection of cognitive and behavioral skills that are used to attain, maintain, or regain health. Resourcefulness includes personal resourcefulness, defined as the capability of being independent in daily activities (self-help) despite challenging situations (Zauszniewski, 2006), and social resourcefulness, defined as asking others for assistance when unable to perform tasks alone (Zauszniewski, 2006). Previous research has shown that resourcefulness enhances independence and productivity: persons with high resourcefulness are able to handle adversity and negative life experiences more constructively than persons with low resourcefulness (Bekhet et al., 2008).

It has been noted that the mechanisms by which caregivers/parents of persons with ASD develop physical health problems are not entirely understood (Karst & Van Hecke, 2012). This study examined the associations between self-assessed health, depressive symptoms, positive cognitions, resourcefulness, and well-being in caregivers of persons with ASD. A second purpose was to assess whether depressive symptoms, positive cognitions, resourcefulness, and well-being will differ significantly between those who rated their health as fair, good, or excellent.

The study will address the following research questions:

- 1. Is there an association between self-assessed health and depressive symptoms, positive cognitions, resourcefulness, and well-being in caregivers of persons with ASD?
- 2. Is there a statistically significant difference between those who reported their health as good, fair, or excellent in relation to depression?
- 3. Is there a statistically significant difference between those who reported their health as good, fair, or excellent in relation to positive cognitions?
- 4. Is there a statistically significant difference between those who reported their health as good, fair, or excellent in relation to resourcefulness?
- 5. Is there a statistically significant difference between those who reported their health as good, fair, or excellent in relation to well-being?

Methods

Design

The study was a secondary analysis of data from a cross-sectional study of 109 caregivers of persons with ASD. The original study used a descriptive and cross-sectional design to assess the psychometric properties of the Positive Thinking Skills Scale and used positive cognitions, resourcefulness, depression, and well-being as construct validation measures; Institutional Review Board approval was obtained in the parent study (Bekhet & Zauszniewski, 2013). In the original study, convenience sampling of ASD caregivers were recruited from the Interactive ASD Network Research registry service sponsored by the ASD Speaks Foundation.

Instruments

Depression was measured by the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). The CES-D is a 20-item Likert-type scale ranging from 0 "rarely or none of the time" to 3 "most or all of the time"; it was initially designed to evaluate depressive symptoms in adults. However, research has shown that the CES-D is reliable and valid in general and clinical populations as well (Radloff, 1977). Subjects are asked to indicate how frequently they have experienced depressive feelings and behaviors during the past week. Scores may range from 0 to 60, after reverse coding four items, with higher scores indicating the presence of more depressive symptoms.

The CES-D is reliable as evidenced by a Cronbach's alpha of .92 in mothers of persons with ASD (Ekas, Whitman, & Shivers, 2009). Factor analysis resulted in four factors accounting for 48% of the variance. CES-D correlated significantly with the Hamilton Rating Scale and the Raskin Rating Scale, suggesting construct validity (Radloff, 1977).

The Depressive Cognitions Scale (DCS; Zauszniewski, 1995) is an 8-item scale that measures positive cognitions when scoring is not reversed as all the items are phrased positively. The scale has also been used in previous studies to measure positive cognitions (Bekhet et al., 2008). The 8-item scale uses a 6-point Likert scale ranging from strongly disagree (0) to strongly agree (5). Possible range of scores is zero to 40, with the higher scores indicating more positive cognitions (Zauszniewski, 1995). The DCS is reliable, as demonstrated by Cronbach's alpha of .90 in ASD caregivers (Bekhet et al., 2012). Construct validity was supported by correlations in the expected directions with caregiver burden (r = .40; p < .001), resourcefulness (r = -.65; p < .001), sense of coherence (r = -.77; p < .001), and quality of life (r = -.70; p < .001; Zauszniewski & Suresky, 2010). Factor analysis revealed one factor that explained 48% of the variance (Zauszniewski & Suresky, 2010).

The Resourcefulness Scale is composed of 28 items that measure both personal resourcefulness and social resourcefulness. Caregivers report the degree to which each item describes their behaviors on a 6-point Likert scale ranging from extremely nondescriptive (0) to extremely descriptive (5). Possible range of scores is 0–140; with the higher scores reflecting greater resourcefulness. The scale is reliable as indicated by a Cronbach's alpha of .85. Evidence of construct validity was evidenced by confirmatory factor analysis indicating the presence of the two forms of resourcefulness: personal resourcefulness and social resourcefulness. The strong intercorrelations between the two identified factors (personal and social) also indicated the scale's construct validity (Zauszniewski, Lai, & Tithiphontumrong, 2006).

The General Well-Being (GWB) Schedule was used to measure well-being (Dupuy, 1984). GWB is a selfadministered questionnaire that offers a broad indicator of well-being and distress. The questionnaire is composed of 18 items; 14 items are rated on a 6-point Likert scale indicating frequency, and the other 4 items use 0–10 rating scales defined by adjectives at each end. Scores may range from 0 to110; 14 is subtracted from the total score. Scores of 0–60 reflect severe distress, 61–72 reflect moderate distress, and 73 to 110 reflect positive well-being (Dupuy, 1984). Reliability of the scale was evidenced by a Cronbach's alpha of .92 (Taylor et al., 2003). GWB was correlated significantly with Zung's Self-Rating Depression Scale (r = .66) and with the Personal Feeling Inventory (r = .78) indicating construct validity (Fazio, 1977).

Perceived health status was measured by an index based on a 4-point Likert-type scale; scores were calculated based on participants' rating of their present health 1 (*poor*) to 4 (*excellent*); the higher the score, the better the health (Musil, Haug, & Warner, 1998). This single-item indicator of self-assessed health has been used in previous studies and proved to be a valid indicator of subjective appraisal of health status (Bekhet et al., 2008; Idler & Kasl, 1991; Musil et al., 1998).

Data Analysis

Data were analyzed using the PASW Statistical Package for the Social Sciences version 18.0 (Allen & Bennett, 2010). Descriptive statistics were used to examine the demographics and main study variables. Pearson correlations were used to examine the associations between self-assessed health and depressive symptoms, positive cognitions, resourcefulness, and well-being in caregivers of persons with ASD. One-way analysis of variance and a Tukey's post hoc test were used to examine differences in depression, well-being, positive cognitions, and resourcefulness between those who reported their health as good, fair, or excellent.

Results

The average age of caregivers of persons with ASD in this study was 42 years; 96% (*n* = 105) of the caregivers were women and four were men. The majority (88%) were Caucasian (*n* = 96). Approximately one fifth (21.1%) reported their health as fair, 55% reported their health as good, and 23.9% reported their health as excellent. No subjects rated themselves as having poor perceived health. Regarding education, more than one third of the sample (almost 38%) had a college degree, 31% completed an associate degree, almost 27% had completed a graduate degree, and only 4% reported completing a high school diploma. Approximately, 58% reported an annual income equal to or greater than \$45,000 (Bekhet & Zauszniewski, 2013). The majority of the caregivers were married (81.7%), 12.8% were either divorced or separated, and 5.5% reported that they have never been married.

All the caregivers except two lived in the same household with the person with ASD; 80.7% (n = 88) reported that they provided care with daily activities to their family member who had ASD (Bekhet & Zauszniewski, 2013). 15.6% (n = 17) reported that they provided some cares, and only 3.7% (n = 4) reported that they do not provide care. 44% of the caregivers reported that they received help either from therapists, home health care, and day care. Of the caregivers, 19.3% reported that they received much help from school and or after school programs. Some caregivers indicated that family members and babysitters helped in providing care.

The correlation matrix for all study variables is shown in Table 1. There were significant (p < .001) positive correlations between self-assessed health and positive cognitions, resourcefulness, and wellbeing (r = .31, .31, .49, respectively) and a significant negative correlation between self-assessed health and depression (r = -.32; p < .001). Also, we did run a correlational matrix between years since diagnosis, caregivers' marital status, education, income, and the major study variables. However, we did not find significant correlations between these demographics and the main study variables (Table 2); therefore, we did not control for any of those variables statistically.

Table 1. Correlations Among Major Study Variables

	Positive cognitions	Resourcefulness	Depression	Well-being
Self-assessed health	.31*	.31*	32*	.49*

• **p* < .001.

	Self-assessed health	Positive cognitions	Resourcefulness	Depression	Well- being
Years since diagnosis	.09	02	14	.04	.04
Income	.14	.09	.05	09	.03
Education	.04	.005	04	.004	11
Marital status	03	12	.04	.16	.12

Table 2. Correlations Among the Demographics and the Major Study Variables

Self-Assessed Health and Caregivers' Depression

There was a statistically significant difference between groups as determined by one-way analysis of variance (ANOVA; F(2,106) = 7.17, p = .001; Table 3). A Tukey post hoc test revealed that depression was statistically significantly lower among those who rated their health as excellent (9.88 ± 7.76, p = .002) than among those who rated their health as fair (21.43 ± 14.84, p = .002) and as good (18.58 ± 11.52, p = .005; Table 4). There were no statistically significant differences between those who rated their health as fair (p = .575).

Table 3. Test Statistics and *p*-Values of Analysis of Variance

Variables	F	<i>p</i> -value
Positive cognitions	6.53	.002
Resourcefulness	6.08	.003
Depression	7.17	.001
Well-being	18.72	.001

Table 4. Descriptive for the Main Study Variables by Self-Assessed Health

Variable		N	Mean	Standard deviation
Positive cognitions	Fair	23	29.52	7.04
	Good	60	33.17	4.21
	Excellent	26	34.42	4.38

	Total	109	32.70	5.22
Resourcefulness	Fair	23	81.74	16.67
	Good	60	93.43	17.38
	Excellent	26	98.92	19.02
	Total	109	92.28	18.45
Depression	Fair	23	21.43	14.84
	Good	60	18.58	11.52
	Excellent	26	9.88	7.76
	Total	109	17.11	12.21
Well-being	Fair	23	53.17	17.30
	Good	60	60.33	12.00
	Excellent	26	75.62	12.72
	Total	109	62.47	15.48

Self-Assessed Health and Caregivers' Positive Cognitions

There was also a significant difference between groups as determined by one-way ANOVA, *F* (2,106) = 6.525, p = .002 (Table 3). A Tukey post hoc test revealed that positive cognitions were significantly higher among those who rated their health as excellent $(34.42 \pm 4.38, p = .002)$ than among those who rated their health as fair $(29.52 \pm 7.04, p = .002)$ and/or good $(33.17 \pm 4.22, p = .005;$ Table 4). There were no statistically significant differences between those who rated their health as good and those who rated their health as excellent (p = .531).

Self-Assessed Health and Caregivers' Resourcefulness

Similarly, there was a significant difference in resourcefulness between the groups, as determined by one-way ANOVA, F(2,106) = 6.079, p = .003 (Table 3). A Tukey post hoc test revealed that resourcefulness was significantly higher among those who rated their health as excellent (98.92 ± 19.02, p = .003) than among those who rated their health as fair (81.74 ± 19.02, p = .022) and between those who rated their health as good (93.43 ± 17.38, p = .022) as compared with those who rated their health as fair (93.43 ± 17.38, p = .022; Table 4). There were no statistically significant differences between those who rated their health as good and those who rated their health as excellent (p = .384).

Self-Assessed Health and Caregivers' Well-Being

Finally, there was a significant difference in well-being between the groups as determined by one-way ANOVA, F(2,106) = 18.72, p = .001 (Table 4). A Tukey post hoc test revealed that well-being was statistically significantly higher among those who rated their health as excellent (75.61 ± 12.72, p < .001) than among those who rated their health as fair (53.17 ± 17.30, p < .001), and those who rated their health as good (60.33 ± 11.99, p < .001; Table 4). There was no statistically significant difference between those who rated their health as good and those who rated their health as fair (p = .080).

Discussion

The study was the first to investigate the relationship between self-assessed health and depression, positive cognitions, resourcefulness, and well-being. The findings indicate that depression was significantly lower among those who rated their health as excellent than among those who rated their health as fair or good. These findings are consistent with a previous study that found that poor self-assessed health was significantly associated with major depressive episode in a sample of 1,843 subjects 50–91 years old (Tintle, Bacon, Kostyuchenko, Gutkovich, & Bromet, 2011).

This study also indicated that positive cognitions were significantly higher among those who rated their health as excellent than among those who rated their health as fair or good. This is consistent with other studies that found that positive cognitions improved mental health and increased a person's ability to deal with daily life events and activities more efficiently (Zauszniewski et al., 2002). Similarly, resourcefulness was significantly higher among those who rated their health as excellent than among those who rated their health as fair and between those who rated their health as good as compared with those who rated their health as fair. Previous studies have found that resourcefulness helped patients with chronic illnesses to better cope with their disabilities, and lead a more independent, healthy, and productive life style (Aikens, Wallander, Bell, & Cole, 1992; Braden, 1990; Zauszniewski, Bekhet, Lai, McDonald, & Musil, 2007).

Limitations

Limitations of this study include the use of a convenience sample of caregivers who used the Internet. Internet recruitment can be a limitation because we can generalize our findings only to those who use the Internet. Other caregivers who do not use the Internet may have different characteristics/background. On the other hand, the Internet enabled the researchers to recruit a national sample. Another limitation is that the study was cross-sectional, so changes in study variables could not be assessed over time. For example, over time, caregivers might develop resilience and adapt to the caregiver role or, they might experience fatigue and exhaustion. Therefore, longitudinal studies might be beneficial in evaluating the effects of self-assessed health, depression, and protective factors on caregivers of persons with ASD. In addition, this study was a secondary analysis of existing data; therefore, some variables were not available, such as the severity of symptoms, although this could be related to caregivers' self-assessed health and resourcefulness. Future studies should measure the severity of depressive symptoms and its relationship to caregivers' self-assessed health over time. A final limitation addresses the potential impact of variables that were not controlled for or captured on the perception of health; most notably perhaps is time in the caregiver role. Although the author did collect data regarding "time since diagnosis;" the actual time identified might vary from the actual time in the caregiver role as caregiving might have occurred before the official diagnosis of their son/daughter. Therefore, longitudinal studies should begin to bridge the reported results in this study to additional factors contributing to levels of self-reported health such as time in the caregiver role, being a caregiver of more than one child diagnosed with ASD, and personality type.

Implications for Nursing Practice

The current study found that self-assessed health was significantly and positively associated with positive cognitions, resourcefulness, and well-being, and significantly and negatively associated with

depression. It has been pointed out that maintaining the good health and well-being of parents of persons with ASD is vital for optimal care for these children (Tomislav, Vuletić, & Ivana Pavić, 2009). Therefore, interventions should include improvement of parents' health and well-being. It is also documented that depressive states can lead to lack of self-care and poorer self-assessed health (Unutzer & Bruce, 2002). Thus, poor self-assessed health may lead to more depressive symptoms, and more depressive symptoms may also lead to poorer self- assessed health. Nursing interventions directed toward minimizing depressive symptoms in parents of those with ASD may bring increased energy, interest, ability to concentrate, and hope for the future. ASD caregivers may then be better able to begin to address self-care needs.

Mental health practitioners are in a strategic position to provide cognitive behavioral interventions to help caregivers fight depression and enhance their quality of life. It has been pointed out that a cognitive behavioral approach is beneficial in enhancing self-image and self-efficacy beliefs, as well as modifying perceptions (Bekhet, ElGuenidi, & Zauszniewski, 2011; Rush & Beck, 2000). In light of these study findings, interventions to increase positive cognitions and resourcefulness should be considered to alleviate the depression and improve the well-being of caregivers. A previous study found that positive cognitions decreased depressive symptoms in women with diabetes (Zauszniewski et al., 2002), and helped older adults to deal with distressing life events such as relocation more positively (Bekhet, Fouad, & Zauszniewski, 2011), and to reduce the burden associated with caregiving of persons with serious mental illness (Zauszniewski, Bekhet, & Suresky, 2009). Positive cognitions interventions might include helping caregivers to identify the pessimistic thoughts that might overwhelm their lives. It also includes helping them to transform their negative thoughts into positive ones. In addition, it includes teaching them how to highlight the positive aspects of the situation and how to interrupt pessimistic thoughts by using relaxation techniques and distraction. Also, teaching them how to practice these positive strategies rather than just knowing them are essential (Bekhet & Zauszniewski, 2013). Interventions to increase social resourcefulness might include: teaching caregivers how to rely on family and friends when needed as well as how to exchange ideas with other caregivers, and how to seek professional help when necessary (Zauszniewski, 2006). Personal resourcefulness interventions might include: organize daily activities so things seems manageable, use positive self-talk, and reframe the situation positively (Zauszniewski, 2006).

In addition, the Depressive Cognition Scale (DCS) can be used to assess the depressive cognitions in caregivers of persons with ASD. The DCS is a brief measure 8-item scale that takes only 5 min to complete and can be used to detect the depressive cognitions that precede the development of clinical depression. Therefore, it can be used as a primary intervention for early detection of depressive thoughts so that cognitive interventions can be initiated early before the development of clinical depression (Zauszniewski, 1995). In addition, the use of video feedback can help caregivers change their ways of approaching challenging situations (Roter et al., 2004).

In brief and in the light of the study findings, depression among caregivers of persons with ASD should be screened for and treated. Also, caregivers should be taught coping skills such as resilience, positive cognition, and ways in which to increase well-being so that that they may experience better perceived health and thus be more capable in coping with the challenges of caring for children with ASD. In terms of future research, longitudinal studies could examine the effectiveness of interventions to enhance positive cognitions, resourcefulness, and well-being among caregivers of people with ASD, and to determine their effectiveness in reducing depression and their effects on the physical health among these caregivers. The effects of these interventions could be measured on a timed schedule such as immediately, after six weeks, and again at 3 months post-intervention so that the researchers would be informed as to the effectiveness of positive cognition and resourcefulness interventions on depression and physical and psychological well-being over time.

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