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Online Positive Thinking Training Intervention for Caregivers of Individuals with ASD: Necessity, Acceptability and Feasibility

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ABSTRACT

Background: More than 3.5 million people in the United States are diagnosed with autism spectrum disorder (ASD). Caring for children with ASD can be stressful and can be detrimental to the well-being of the caregivers (CGs). However, the adverse effects of caregiving on the well-being of CGs may be avoided with appropriate interventions. CGs of persons with ASD might benefit from a positive thinking training (PTT) intervention to help them cope with the stress of caregiving. However, the necessity, acceptability and feasibility for PTT in ASD CGs have not been studied.

Objective: To examine the necessity, acceptability and feasibility of a six-week online PTT intervention designed to improve the well-being of the CGs.

Design: Random assignment of ASD CGs to one of two conditions: (1) PTT online intervention or (2) Control group.

Results: The mean score on the depressive cognition scale (DCS) was 20, indicating a high need of PTT to all enrolled CGs. High depressive cognitions in ASD CGs were associated with lower positive thinking ($r = -.39$; $p < .001$). Regarding acceptability, CGs indicated that the different strategies and references to real life were the most interesting parts of the intervention. Regarding feasibility, CGs mentioned that listening to the voice-over PowerPoint and visualization was the easiest part of the PTT.

Conclusions: Examination of the fidelity and effectiveness of the PTT are the next steps in the refinement of this intervention.

Introduction

More than 3.5 million people in the United States are diagnosed with autism spectrum disorder (ASD). According to the Diagnostic criteria of Diagnostic and Statistical Manual of Mental Disorders (DSM-V), ASD is spectrum of complex neurological and developmental disorders characterized by persistent deficits in social communication and social interaction across multiple contexts as manifested by deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviors, and deficits in developing, maintaining, and understanding relationships. In addition to the presence of restricted, repetitive patterns of behavior, interests, or activities as manifested by stereotyped, or repetitive motor movements, insistence on sameness, inflexible adherence to routines, and hyper- or hyporeactivity to sensory input (American Psychiatric Association [APA], [2013](#)). These deficits are lifelong and are pervasive in nature, which can have deleterious effects on caregivers' (CGs) physical and psychological well-being (Altiere & Von Kluge, [2009](#); Bekhet, [2014](#); Karst & Van Hecke, [2012](#); Phetrasuwan & Miles, [2009](#)). Previous research has shown that parents of persons with ASD are clinically depressed, as compared to parents of normally developed children (Benson, [2006](#)). The impact of symptoms severity of depressed mood among parents of children with ASD.; Davis & Carter, [2008](#). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. Karst & Van Hecke, [2012](#). Parent and family impact of autism spectrum disorders. They also reported higher levels of fatigue, physical problems, and lower self-perceived health than parents of typically developed children (Allik, Larsson, & Smedje, [2006](#)). Health-related quality of life in parents of school-age children with Asperger syndrome or high-functioning autism. Benjak, Mavrinac, & Šimetin, [2009](#). Comparative study on self-perceived health of parents of children with autism spectrum disorders and parents of non-disabled children in Croatia. Mugno, Ruta, D'Arrigo, & Mazzone, [2007](#). Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. Smith et al., [2010](#). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. However, the adverse effects of ASD caregiving on the well-being of CGs may be avoided or ameliorated with appropriate interventions.

Previous research has shown that individuals with greater positive thinking have a better capability to deal with stressful situations, better adaptive functioning, as well as an enhanced quality of life in various populations (Dekker, Peden, Lennie, Schooler, & Moser, [2009](#); Jung et al., [2007](#); Lightsey & Boyraz, [2011](#)). Positive thinking is a cognitive process that helps individuals to create hopeful images, find favorable solutions to problems and produce an overall bright outlook on life (Bekhet & Zauszniewski, [2013](#)). Positive thinking acknowledges both the negative and positive aspects of situations, and then favors movement towards a positive focus and interpretation. Positive thinking has been suggested as a useful strategy for coping with adversity (Bekhet & Zauszniewski, [2013](#)).

A descriptive research study conducted by Bekhet and colleagues ([2012](#)) has shown that positive thinking attenuated the effects of CGs' burden and enhanced their levels of resourcefulness and psychological well-being in a sample of 95 CGs of persons with ASD (Bekhet, Johnson, & Zauszniewski, [2012](#)). It has been pointed out that "research on interventions designed to help individuals with ASD and their families has been comparatively more limited" (Karst & Van Hecke, [2012](#)). In fact, CGs of persons with ASD might benefit from a positive thinking training (PTT) intervention to help them cope with the stress of caregiving. However, the necessity, acceptability and feasibility for PTT in ASD CGs have not been studied.

It has been suggested that it is essential to study the need for an intervention, such as PTT, in this case, from the CGs' perspectives. This is because their perceived need is likely to affect their interest and performance of the intervention, and ultimately, its impact on their health (Zauszniewski, [2012](#)).

Acceptability of an intervention refers to whether or not participants believe that what they are being asked to do is reasonable or appropriate for them (Bekhet, Zauszniewski, & Matel-Anderson, [2012](#); Zauszniewski, [2012](#)). Feasibility of an intervention refers to whether or not individuals believe that what they are being asked to do is manageable and practical for them. In fact, necessity, acceptability and feasibility are important parameters that need to be assessed as part of an intervention (Bekhet, Zauszniewski, et al., [2012](#); Zauszniewski, [2012](#)).

Purpose

The purpose of this pilot intervention study was to determine:

1. The need for the PTT intervention by addressing the following questions: (1) what percentage of ASD CGs scored high on the depressive cognition scale (DCS), indicating a high need for PTT; (2) whether high depressive cognition in ASD CGs was associated with lower positive thinking; (3) whether ASD CGs who dropped out of the study and those who continued differed on measures of depressive cognition; (4) What reasons ASD CGs gave for dropping out of the PTT intervention; (5) what percent of ASD CGs who completed PTT said they believed they needed it and what percent believed that other ASD CGs would need it.

- II. The acceptability of the PTT from CGs' perspectives by asking the following questions: (1) What part or parts of the intervention were most interesting? (2) What part or parts of the intervention were least interesting? (Bekhet, Zauszniewski, et al., [2012](#); Zauszniewski, [2012](#))
- III. The feasibility of the PTT from CGs' perspectives by asking the following questions: (1) What part or parts of the intervention were easiest? (2) What part or parts of the intervention were most challenging? (Bekhet, Zauszniewski, et al., [2012](#).; Zauszniewski, [2012](#))

Methods

Design

This pilot intervention study involved a random assignment of a convenience sample of CGs of persons with ASD to one of two conditions: (1) PTT online intervention or (2) no intervention/control group.

Sample, setting and data collection

Approval for the study was obtained from the University Institutional Review Board. The researcher contacted the Interactive Autism Network (IAN) Research registry service for subject recruitment. CGs received an IRB-approved flyer through the IAN. An IAN request directed potential CGs to the Internet website (www.surveymonkey.com) where a consent form and a link to the study questionnaires were housed.

The initial sample included 77 CGs, who responded to the online study questionnaires before the intervention (T1), and they were told that their e-mail addresses would be randomly assigned to either an intervention group or to a control group. Two CGs completed only two questionnaires. So, their data were excluded from the study, leaving the study with 75 remaining CGs. Another two CGs did not provide their contact information (e-mail addresses and phone numbers), so they were not assigned to either an intervention group or a control group, leaving the study with a total of 73 CGs for T2. Then, e-mail addresses of the 73 CGs were randomly assigned to either receive the online PTT intervention ($n = 37$) or to be in the control group ($n = 36$). Of the 37 CGs assigned to the intervention group, one CG dropped out after the third week due to family circumstances, as reported by the CG, and the remaining eight CGs withdrew from the study after the first baseline data collection and before receiving the PTT intervention. We tried to contact them several times, but they did not respond to our e-mails/phone calls and did not participate in any of the six-week interventions, leaving the study with a total of 28 remaining CGs in the PTT intervention group. Each CG in the control and the intervention group received a \$20 Amazon gift card after T1 and a \$35 Amazon gift card after T2. Data were collected during the months of October, November and December of 2015. All the data were collected online (baseline and one week post-intervention). The PTT intervention was provided between the first and second data collection. The remaining sample of 64 CGs (control = 36 and experimental = 28) was considered sufficient for examining descriptive statistics and for identifying correlations between depressive cognitions and positive thinking at a significance level of $\alpha = .05$ and power of $B = .80$ (Cohen, 1992).

The positive thinking training intervention

Six voice-over PowerPoint presentations using the acronym THINKING were created and delivered to CGs. The first video (video 1) was an introduction to the PTT intervention and the acronym THINKING. One video was delivered to the CGs in the online PTT intervention group each week as follows: **T**ransform negative thoughts into positive thoughts; **H**ighlight positive aspects of the situation (video 2); **I**nterrupt pessimistic thoughts by relaxation techniques and/or distractions; **N**ote the need to practice positive thinking (video 3); **K**now how to break a problem into smaller parts to be manageable; **I**nitiate optimistic beliefs with each part of the problem (video 4); **N**urture ways to challenge pessimistic thoughts (video 5); and **G**enerate positive feelings by controlling negative thoughts (video 6). The skills of the PTT intervention reflect cognitive activities to increase positive thoughts and to eliminate or modify negative ones (Bekhet & Zauszniewski, [2013](#)). Acronym and chunking were used to facilitate learning positive thinking skills (Bekhet & Zauszniewski, [2013](#); Hampstead et al., [2012](#)). The acronym uses the eight letters that spell the word THINKING to prompt recall of specific Positive Thinking skills. Chunking refers to the common rule that a person can remember between five and nine things at one time. The word THINKING contains eight letters, which is a reasonable “chunk” of ideas for CGs to remember (Thornton & Conway, [2013](#)).

Instruments

The Depressive Cognitions Scale (DCS; Zauszniewski, [1995](#)) is an eight-item scale that measures depressive cognitions when scoring is reversed as all the items are phrased positively. The eight-item scale uses a six-point Likert scale ranging from strongly disagree (0) to strongly agree (5). Possible range of scores is zero to 40, with higher scores indicating more depressive cognition after reverse coding the eight items. The DCS is reliable, as demonstrated by Cronbach's alpha of .90 in ASD CGs (Bekhet, Johnson, et al., [2012](#)). Construct validity was supported by correlations in the expected directions with CG 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](#)).

Positive Thinking Skills Scale (PTSS; Bekhet & Zauszniewski, [2013](#)) is an eight-item scale that measures positive thinking as a direct measure of intervention fidelity. All items are scored in the positive direction; higher scores indicate more positive thinking. The total scale scores will range between 0 and 24, with higher scores indicative of more positive thinking. Response options are four-point Likert scales ranging from 0 = *never* to 3 = *always*. In a study with CGs of persons with ASDs, Bekhet & Zauszniewski ([2013](#)) reported acceptable internal consistency ($\alpha = .90$) and construct validity, using a measure of positive cognitions ($r = .53$; $p < .01$), resourcefulness ($r = .63$; $p < .01$), depression ($r = -.45$; $p < .01$) and general well-being ($r = .40$; $p < .01$) for the Positive Thinking Skills Scale (PTSS). Exploratory factor analysis indicated the presence of a single factor with all item factor loadings exceeding .30; 59% of the total variance was explained.

Other measures of PTT need

In addition to the demographic questionnaire and scales measuring depressive cognitions and positive thinking, we tracked CGs attrition in order to determine if their reasons reflected a perception of little need for the PTT intervention. Then, at the end of the study, we asked the autism CGs who received the PTT intervention if they believed they needed the intervention and if they felt that other CGs of Persons with ASD might need the intervention.

Measures of acceptability and feasibility

Acceptability of the intervention was assessed by asking ASD CGs to describe what part or parts of the intervention were most and least interesting and whether they thought that the intervention content was appropriate for them. The feasibility of the PTT intervention was evaluated by asking ASD CGs to describe what part or parts of the intervention were easiest, which was most challenging, and if they thought that the length of the online sessions was appropriate in terms of time commitment.

Analysis

Data were analyzed using the IBM Statistical Package for the Social Sciences software version 22. Descriptive statistics were used to examine the sample characteristics and the baseline depressive cognition scores. Pearson correlations were used to examine the associations between depressive cognition and positive thinking in CGs of persons with ASD. The independent samples *t*-test was used to compare ASD CGs who dropped out of the study and those who continued on measures of depressive cognition. Content analysis was used to answer the qualitative questions related to the necessity, acceptability and feasibility of the PTT intervention.

Results

Sample characteristics

The average age of the 64 CGs who completed time 1 and time 2 (28 control and 36 intervention) was 37.5 (St. D. = 7) with a range between 24 and 61 years old. The majority of the sample consisted of women (94%). More than two-thirds of the participants in the sample were married (70.3%). The majority of the sample was Caucasian (82.8%), and the remaining identified themselves as either: African American, Hispanic or other. Approximately, 19% reported having more than one child diagnosed with ASD. 95% of the CGs reported themselves as mothers of persons with ASD, and the remaining were fathers of the persons with ASD. All CGS reported living with the person with ASD in the same household, and the majority (89%) reported providing care with daily activities. 43.8% ($n = 28$) reported receiving no help, 29.7% ($n = 19$) reported receiving help from other family members, and over one quarter of the sample reported receiving help from other sources such as day care, school, friends, ABA therapy and babysitters.

On the other hand, the average age of persons with ASD was found to be 7.6 (St. D. = 3.7). More than two-thirds of persons with ASD were boys (78.1%), and more than two-thirds of persons with ASD were Caucasian ($n = 50$), representing 78.1%. The other ethnicities were either African American, Hispanic or others.

The need for the PTT intervention

Baseline depressive cognition and the need for positive thinking training

Scores on the DCS were examined at baseline for all CGs initially enrolled in the study and who completed the study questionnaires ($n = 75$). The possible range of scores on the eight-item DCS can range from 0 to 40, with higher scores indicating more depressive cognition after reverse coding the eight items. To determine CGs' need for PTT, we used the cutoff score of seven on the DCS (Zauszniewski & Bekhet, [2012](#)). Previous research supports the cutoff score of seven as optimal in identifying the probable presence of significant depressive thinking patterns that might lead to clinical depression while limiting the overidentification of persons not likely to have clinically significant depressive symptoms (i.e., false positives) (Zauszniewski & Bekhet, [2012](#)). All 75 CGs in this study scored between 11 and 28 with a mean score of 20 and a St. Deviation of 4.8, indicating the presence of depressive thinking patterns.

The relationship between depressive cognition and positive thinking

High depressive cognitions in ASD CGs were associated with lower positive thinking ($r = -.39$; $p < .001$).

ASD caregivers who dropped out of the study and those who continued on measures of depressive cognition

ASD CGs who dropped out of the study and those who continued did not differ significantly on measures of depressive cognition [$(t = 73) = -1.50$, $p = .137$].

Reasons for withdrawing

A total of nine CGs dropped out of the intervention group before starting the intervention; they neither accessed the website nor participated in any of the 6-week interventions. They just participated in T1 data collection and withdrew after receiving the \$20 gift card. Among the nine CGs, eight CGs did not respond to e-mails and phone calls, and one CG dropped out after the third week due to family circumstances, as reported by the CG. None of the eight CGs gave a reason for withdrawing.

Caregivers' perception of the need for the PTT

Of the 28 CGs who completed the PTT, 82% reported a felt need for PTT ($n = 23$), and 89% believed that other ASD CGs need PTT.

Acceptability of the PTT intervention from Caregivers' perspectives

Regarding acceptability, 14 of the 28 CGs stated that the whole PTT intervention was interesting and that nothing was least interesting. Nine CGs indicated that the strategy of turning negative thoughts into positive ones was the most interesting. Three indicated that the 'specific, concrete examples, and the different suggestions and references to real life was the most interesting'. One CG indicated the strategy of breaking the problems into smaller parts, so things seemed more manageable were the most interesting. On the other hand, two CGs indicated that the first week was "a little slow moving" and was the least interesting. Of interest, while three indicated that the relaxation techniques were the least interesting, four other CGs indicated that the relaxation techniques were the most interesting.

Feasibility and of the PTT intervention from Caregivers' perspectives

Regarding feasibility, eleven CGs (39%) mentioned that listening to the voice-over PowerPoint and visualization was the easiest part of the intervention. One CG mentioned that he/she liked that the intervention was broken down into smaller parts 'The fact that the information was broken down into small parts; it made it doable. Finding 1+ hours can be hard, but finding 5–7 minutes was not difficult at all—it made getting through the various videos achievable (and something) I could feel good about as opposed to feeling bad for agreeing to something and then not being able to follow through'. Three CGs mentioned that the most challenging part was finding time; one CG mentioned, 'I'm trying to incorporate relaxation techniques, it required the most time of which I have the least'. CGs' opinions regarding the most challenging and the easiest part of the intervention varied. While four CGs mentioned that the strategy of 'breaking problems into smaller parts' was the easiest, another two CGs mentioned that this strategy was the most challenging. Seven of the 28 CGs mentioned that remembering to use them as an everyday routine was the most challenging; one CG mentioned 'trying to remember to do it during my daily routine'.

Discussion

This is the first study that evaluated the necessity, feasibility and acceptability for PTT intervention from ASD CGs' perspectives. The data from this study demonstrated a need for PTT for CGs of persons with ASD. All CGs in this study exceeded the cutoff score of seven on the DCS, indicating the presence of depressive thinking patterns (Zauszniewski & Bekhet, [2012](#)). Moreover, the inverse relationships between positive thinking and depressive cognitions among CGs of persons with ASD suggested that low positive thinking poses a risk to the psychological well-being of CGs for persons with ASD. Previous studies also have shown a high risk of depression and stress among CGs of persons with ASD, which are indicators of a high need for PTT, among individuals with low positive thinking (Bekhet, [2016](#); Ekas, Lickenbrock, & Whitman, [2010](#). Firth & Dryer, [2013](#)). Assessing the need for an intervention from the intervention recipients' perspective, CGs of persons with ASD in this case, is critical because their perceived need for the intervention will likely affect their future use of the PTT intervention and, hence, improve their health and well-being (Bekhet, Johnson, et al., [2012](#); Zauszniewski, [2012](#)). In this study, a large majority of ASD CGs (82%) who completed the PTT

felt that they needed this training, and 89% of the CGs also believed that other ASD CGs would benefit from the training. This study is one of few that have assessed the need for intervention from the recipients' perspectives and also used an objective indicator to assess their actual need (Bekhet, Johnson, et al., [2012](#); Zauszniewski et al., [2012](#)). Five CGs of the 28 CGs who received the intervention felt that they did not need the PTT, but they exceeded the cutoff scores of seven on the DCS at baseline, indicating a need for PTT intervention. Thus, participants' subjective perception of need may not always match objective indicators.

The results of this study are similar to those of a previous study conducted by Zauszniewski and colleagues that assessed the need for resourcefulness training for women CGs of elders with dementia (Zauszniewski, Lekhak, Yolpant, & Morris, [2015](#)). Their results indicated that eleven CGs felt they did not need the training, but only three scored low on need on the Resourcefulness Scale at baseline. The authors also concluded that dementia CGs' perception of need may not always match objective indicators (Zauszniewski et al., [2015](#)).

However, as a whole, this study found a high resemblance between self-appraised and objectively evaluated needs for positive thinking among CGs of persons with ASD. This, in fact, is similar to the results of previous studies on grandmother CGs (Zauszniewski, Au, & Musil, [2012](#); Zauszniewski et al., [2015](#)) and older adults (Bekhet, Johnson, et al., [2012](#)), indicating that most of the participants' perceived needs matched with their actual need for the intervention. In the study reported here, we measured the need for the PTT intervention by evaluating the baseline DCS and CGs' responses for perceived need post-intervention. Since we added an objective indicator, it helped us to compare the objective data with subjective data, providing validity to the perceived need of the PTT intervention (Zauszniewski et al., [2012](#)). In this study, all ASD CGs exceeded the cutoff scores of seven on the DCS, indicating a high need for the PTT intervention. The findings from this study indicate the need to move forward to test the effectiveness of the PTT for CGs of persons with ASD to reduce their stress and depressive symptoms.

Both acceptability and feasibility of the PTT intervention were generally supported in this study, which is important because of the nature of the sample. This sample, with a mean age of 37.5 years, was similar to samples of ASD CGs participating in other studies (Bekhet, [2014](#), [2016](#)). In fact, the wide range of CGs' ages, from 24 to 61 years, suggests that the intervention can be practiced by CGs of all age groups. However, it should be noted that the findings can be generalized only among ASD CGs who used the Internet.

Of interest, while three indicated that the relaxation techniques were the least interesting, four other CGs indicated that the relaxation techniques were the most interesting. Indeed, the PTT intervention provided the CGs with plenty of strategies and techniques to choose from. So, CGs can pick up the strategy/technique suitable for their interest and time.

Of note, seven of the 28 CGs mentioned that remembering to use the strategies in everyday routine is the most challenging. This, in fact, might reflect the need for giving more time for the CGs to practice what they have learned. Therefore, it is recommended that future research might use multiple time points; i.e., measuring the impact of the PTT intervention after six weeks and twelve weeks post intervention.

A total of nine CGs dropped out of the intervention group before starting the intervention; they neither accessed the website nor participated in any of the six-week interventions. They just participated in T1 data collection and withdrew after receiving the \$20 gift card. Among the nine CGs, eight CGs did not respond to e-mails and phone calls, and one CG dropped out after the third week due to family circumstances, as reported by the CG. None of the eight CGs gave a reason for withdrawing. Therefore, we do not know exactly their reasons for withdrawing. Thus, the results of the study should be interpreted with caution. Future research replication is recommended with a larger sample size.

Having established the need for PTT in CGs of persons with ASD and its acceptability and feasibility in the study reported here, examination of the fidelity and effectiveness of the PTT intervention are the next steps in the development and refinement of the PTT intervention.

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Conflict of interest

The author declares that there is no conflict of interest.

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