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Accepted version. *Archives of Psychiatric Nursing*, Vol. 31, No. 3 (June 2017): 306-310. DOI. © 2017
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Positive Thinking Training Intervention for Caregivers of Persons with Autism: Establishing Fidelity

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ABSTRACT

More than 3.5 million in the US are diagnosed with [autism spectrum disorder](#) (ASD) and caregivers experience stress that adversely affects their well-being. Positive thinking training (PTT) intervention can minimize that stress. However, before testing the effectiveness of PTT, its fidelity must be established. This pilot [intervention trial](#) examined fidelity of an online PTT intervention for ASD caregivers with a random assignment of 73 caregivers to either the online PTT intervention or to the control group. Quantitative data [Positive Thinking Skills Scale (PTSS)] and qualitative data (online weekly homework) were collected. The mean scores for the PTSS improved for the intervention group and decreased for the control group post intervention. Evidence for use of PTT was found in caregivers' online weekly homework. The findings provide evidence of the implementation fidelity of PTT intervention and support moving forward to [test PTT](#) effectiveness in promoting caregivers' well-being.

KEYWORDS

Caregivers, Positive thinking, Fidelity, Autism spectrum disorders, Online intervention

One in sixty-eight children are affected by [autism spectrum disorders](#) (ASD) ([National Autism Association, 2014](#)). It is estimated that > 3.5 million in the United States are diagnosed with ASD ([Autism speaks, 2016](#)). Research showed that the national cost of supporting children and adults with autism is at \$61 and \$175 billion respectively per year, in the US ([Autism speaks, 2016](#)). ASD is a life-long [neurodevelopmental disorder](#) affecting a child's reciprocal communication, social interaction, and behavior patterns ([American Psychiatric Association \[APA\], 2013](#)).

Previous research showed that all caregivers of persons with ASD live with their household full time and almost all (92%) of the caregivers provided care with daily activities ([Bekhet, 2016](#)). The caregivers' age ranged from 23 to 58 years with a mean age of 41, thus many must balance the care of their ASD children with employment outside the home ([Bekhet, 2016](#)). A substantial body of literature has provided evidence that raising a child with ASD is associated with negative [psychological outcomes](#), including depressive symptoms, heightened stress, poorer quality of life, and self-rated health as a result of the burden of caregiving ([Benson and Karlof, 2009](#), [Carbone et al., 2010](#), [Kirby et al., 2015](#), [Phetrasuwan and Miles, 2009](#)). However, research has also shown that caregivers of persons with ASD with greater positive thinking had less burden and better psychological well-being ([Bekhet, Johnson, & Zauszniewski, 2012](#)). In addition, positive thinking was found to have mediating effects on the relationship between caregiver's depression and their children's challenging behaviors ([Bekhet, 2016](#)). Therefore, caregivers of persons with ASD would benefit from a positive thinking training intervention designed to teach caregivers of persons with ASD positive thinking strategies to manage with their daily stressors, which has the potential of positively impacting their psychological well-being as well as the well-being of their care recipients.

IMPORTANCE OF INTERVENTION FIDELITY

In developing an intervention to promote positive thinking in caregivers of persons with ASD, it is important to first establish that the intervention has adequate intervention fidelity.

Fidelity of an intervention involves a competent delivery of the intervention that is in accordance with an outlined protocol ([Zauszniewski, 2012](#)). In other words, intervention fidelity indicates that the intervention is delivered as designed. Ensuring fidelity is essential in enhancing the reliability and the validity of the intervention and it has been linked to enhancing outcomes ([Bellg et al., 2004](#), [Durlak and DuPre, 2008](#)). Lack of fidelity can manifest itself as a gap between the planned and the implemented protocol and it can have an impact on both internal and external validity ([Durlak and DuPre, 2008](#), [McHugh et al., 2009](#)). Five components of intervention fidelity have been identified in the literature namely; design, training, delivery, receipt, and enactment ([Borrelli, 2011](#), [Borrelli et al., 2005](#), [Duffy et al., 2015](#)). The study design is the first component of the intervention fidelity and it is essential as it ensures the avoidance of cross-contamination between both the intervention group and the control group. Training is the second component of the intervention fidelity and it should be standardized

across providers and their skills should be monitored over time. Delivery is the third component which reflects whether the intervention has been delivered as intended and as outlined in the prescribed protocol. Treatment receipt, on the other hand, measures the degree to which the participant understands and applies the skills learned as well as their [confidence levels](#). Enactment is the last component of the intervention fidelity and it measures the actual participation of subjects in the intervention ([Duffy et al., 2015](#)).

It should be noted that the first three components of fidelity include evaluation of activities pertaining to researchers and interventionists. However, the last two components namely, receipt and enactment, focus on the intervention recipient and they are viewed as a response to the first three components of fidelity (design, training, and delivery) ([Michie, 2005](#)).

Despite the fact that receipt and enactment are integral components of the intervention fidelity, they have received less attention ([Gearing et al., 2011](#), [Zauszniewski et al., 2014](#)). Intervention receipt reflect not only the recipient's understanding and usage of the skills taught, but also the application of the skills taught in their daily activities ([Borrelli et al., 2005](#)).

There are many methods of assessing intervention fidelity including pre- and post-survey to ensure that the content was provided/taught ([Zauszniewski, 2012](#)). Another method is by asking the intervention recipients about their application of the skills taught in real life situations ([Zauszniewski, 2012](#)). Although fidelity assessments by intervention recipients are a cost-effective, it is underutilized method for evaluating intervention fidelity ([Essok, Covell, Shear, Donahue, & Felton, 2006](#)).

To date, studies reporting on receipt or enactment of the positive thinking training intervention from the viewpoint of the intervention recipients, in this case caregivers of persons with [autism](#), are absent from the literature. To date, this is the first study to test the fidelity of the positive thinking training intervention from caregivers' perspectives. Therefore, this pilot [intervention trial](#) focused on evaluating receipt and enactment fidelity of the positive thinking training intervention from ASD caregivers' perspectives.

METHODS

DESIGN

This proposed intervention study combines quantitative and qualitative methods in a pilot clinical trial. This mixed [methods, longitudinal](#) study involved a random assignment of a convenience sample of caregivers of persons with ASD to one of two conditions: 1) PTT online intervention or 2) no intervention/control group.

SAMPLE, SETTING, AND DATA COLLECTION

Before the caregivers were identified and recruited, 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. The registry has > 42,000 participants, including approximately 15,000 parents of children with ASD. Caregivers received

an IRB approved flyer through the IAN. An IAN request directed potential caregivers to the Internet website (www.surveymonkey.com) where a consent form and a link to the study questionnaires were housed. Seventy-seven caregivers met the inclusion criteria and responded to the online study questionnaires before the intervention (T1) and they have been told that their e-mail addresses will be randomly assigned to either an intervention group or to a control group (See [Table 1](#)). The final sample included 36 caregivers in the control group and 28 caregivers in the intervention group. Each caregiver received \$20 Amazon gift card after T1 and \$35 Amazon gift card after T2. Data were collected during the months of October, November, and December of 2015. All data were collected online (baseline and one week post-intervention). The PTT intervention was provided between the first and second data collection. In addition, a weekly homework was collected from the PTT intervention group for a total of 5 homework, in which caregivers were asked to indicate a life situation in which they used the PTT strategy after reviewing the weekly video. The first week was an introduction to the PTT intervention with no homework.

Table 1. Study sample and final disposition.

Disposition	Participants, n	
Total who met criteria for inclusion	77 caregivers	
Declined/did not complete the survey	2 caregivers	
Missing contact information necessary for random assignment (phone number and email address).	2 caregivers	
T2	73 caregivers (random assignment)	
	Online PTT intervention (n = 37)	Control group (n = 36).
	1 caregiver dropped after the third week due to family circumstances.	
	8 caregivers did not respond to e-mails and phone calls. They neither access the website nor participate in any of the 6 week interventions.	
Final sample	n = 28	n = 36

THE POSITIVE THINKING TRAINING INTERVENTION

Six voices over PowerPoint presentations using the acronym THINKING were created and delivered to caregivers as follow: **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 part 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 first video (video 1) was an introduction to the PTT intervention and the acronym THNINKING and no homework was required. One video was delivered to the caregivers in the online PTT intervention group each week.

Grounded in cognitive-behavioral theory, the skills of the PTT intervention reflect cognitive activities to increase positive thoughts and to eliminate or modify negative ones ([Bekhet & Zauszniewski, 2013](#)). Three mnemonic strategies were used for the PTT intervention - an acronym and chunking to facilitate learning positive thinking skills and practice to reinforce the learning ([Bekhet and Zauszniewski, 2013](#), [Hampstead et al., 2012](#)). The acronym uses the 8 letters spelling 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 8 letters, which is a reasonable “chunk” of ideas for caregivers to remember ([Thornton & Conway, 2013](#)). For practice, the caregivers were given a homework in which they were asked to indicate a life situation in which they used the PTT strategy after reviewing the weekly video.

INTERVENTIONIST TRAINING AND SUPERVISION OF DELIVERY

The PI wrote the transcript for each of the six videos and gave all of the written transcripts to a [graduate student](#) research assistant for recording. The PI listened to all the recorded videos and multiple recordings were recorded until the voice was clear and understood by two other faculty members. The PI worked with a media production specialist, from the instructional media center at the University, to create six links to secure the voice over PowerPoint presentations. Furthermore, to make it even more secure, we worked with Application Specialist for Learning Technology, to create a course named “Intervention for Caregivers” by accessing the website <https://cps.ce.mu.edu>, in which we posted the links for the PTT intervention. Then, each participant was enrolled from the intervention group by creating accounts. The graduate student research assistant was trained during a single, one hour session on how to read and to record the transcripts.

QUANTITATIVE MEASURES

In addition to a demographic questionnaire, we used quantitative measures to evaluate the fidelity of the PTT intervention. Demographic data on the caregivers (age, gender, education, race, income, perceived health), the ASD child (age, gender, and race), and caregiving situation (relationship to ASD child, living arrangements (with the parent versus apart), amount of caregiving (direct care versus indirect care), and the amount of help received).

The quantitative measure used to capture fidelity was the 8-item Positive Thinking Skills Scale (PTSS) ([Bekhet & Zauszniewski, 2013](#)). It should be noted that the PTSS is designed as a direct measure of intervention fidelity; the PTSS captures **the positive thinking skills taught during the positive thinking training skills intervention** ([Bekhet & Zauszniewski, 2013](#)). It consists of 8 positive thinking skills items with responses on a 4-point Likert scale, ranging

from 0 = never to 3 = always. Scores may range from 0 to 24 with higher scores indicating *more frequent use of positive thinking skills*. Examples of the scale items are: “Transform negative thoughts into positive thoughts” and “Highlight positive aspects of the situation.” The PTSS was found to be internally consistent ($\alpha = 0.90$). Construct validity was supported by significant correlations ($p < 0.01$) with positive cognitions ($r = 0.53$), resourcefulness ($r = 0.63$), depression ($r = -0.45$), and general well-being ($r = 0.40$) ([Bekhet & Zauszniewski, 2013](#)).

QUALITATIVE MEASURES

The fidelity of the PTT interventions was also assessed from qualitative data obtained from the weekly homework recordings of caregivers of persons with ASD who participated in the PTT intervention. We expected that if intervention delivery fidelity was maintained while skills constituting positive thinking were taught during the PTT intervention, the caregivers would write their use of the skills, i.e. mention/describe them by name. Thus, the weekly homework provided qualitative data on whether caregivers used the skills they were taught. Each week, caregivers were asked the following questions:

- What was the positive thinking strategy/strategies that you have learned this week?
- Did you review the voice over PowerPoint presentation of this week?
- Please indicate a life situation or more, in which you have applied the strategy/strategies that you have learned this week. If you did not get the chance to apply what you have learned, please write down 2 or 3 ways you think you might use the first strategy.

Hard copies of the transcripts were reviewed line by line for instances of each caregiver's use of any of the eight positive thinking skills and coding categories were established. The coded transcripts were again reviewed for instances of the eight positive thinking skills. In addition, the fidelity of the intervention was assessed by asking the caregivers whether they thought they learned all the skills constituting positive thinking.

RESULTS

SAMPLE CHARACTERISTICS

CHARACTERISTICS OF CAREGIVERS OF PERSONS WITH ASD

Ages of the 64 caregivers of persons with ASD (28 in the intervention group and 36 in the control group) ranged from 24 to 61 years with an average age of 37.5 (St. D. = 7) and approximately 94% of the sample were females ($n = 60$). More than two thirds of the sample were married (70.3%), and 20% reported themselves as never married, the remaining were either divorced, widowed, or separated. More than half of the caregivers (54.7%) reported their health as good, 28.2% reported their health as poor or fair, and the remaining 17.2% reported their health as excellent. The majority of the sample was Caucasian (82.8%) and the remaining identified themselves as either African American, Hispanic, or others. Almost one fifth of the sample (18.8%) reported having more than one child diagnosed with ASD. More than half of the caregivers (57.8%) reported some college or college degree, 7.8% reported some high

school or high school diploma, and more than a third (34.4%) reported graduate and professional training. More than half of the sample (54.7%) reported incomes \$45,000 or more. The average number of years in terms of providing caregiving was 8 years.

CHARACTERISTICS OF THE PERSONS WITH ASD

Ages of the persons with ASD ranged from 2 to 17 years of age with an average age of 7.6 (St. D. = 3.7). More than two thirds of persons with ASD were males (78.1%). Regarding ethnicity, more than two thirds of the sample were Caucasian (n = 50) representing 78.1%. The other ethnicities were either African American, Hispanic, or others.

Ninety-five percent of the caregivers reported themselves as mothers of persons with ASD and the remaining were fathers of the persons with ASD. All caregivers reported living with the person with ASD in the same household. 89.1% (n = 57) reported providing care with daily activities, and the remaining (n = 7) reported providing some care. 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, Applied Behavioral Analysis (ABA) therapy, and babysitters.

POSITIVE THINKING TRAINING VERSUS COMPARISON (CONTROL) GROUP

Mean scores for the PTT intervention group and the control group on positive thinking were plotted across the two measurement points (baseline and at 6 weeks post-intervention) ([Table 2](#)). As shown in [Table 2](#), the mean scores for the positive thinking improved for the intervention group and decreased for the control group.

Table 2. Positive thinking scores pre- and post-intervention for the intervention group and the control group.

Variable (time)	Intervention group (N = 28) M (St. D.)	Control group (N = 36) M (St. D.)
Positive thinking (baseline)	15.43 (3.99)	16.92 (3.97)
Positive thinking (6-week post-intervention)	17.79 (3.66)	16.58 (4.90)

JOURNALS/ONLINE WEEKLY HOMEWORK

The caregivers in the PTT group described the use of positive thinking skills in their weekly homework. All 28 caregivers completed their first and second weekly homework and 27 caregivers completed the third, the fourth, and the fifth homework. All 28 caregivers indicated in the first and the second weekly homework that they reviewed voice over PowerPoint presentations and they were able to indicate that the name of the strategy/strategies that they have learned. Similarly, all 27 caregivers who completed the third, the fourth, and the fifth homework, indicated that they reviewed the voice over PowerPoint presentation of each week and indicated the name of the strategy/strategies used.

The caregivers in the PTT intervention described the use of positive thinking skills in their online weekly homework. The skills described most frequently were: interrupt pessimistic thoughts by relaxation techniques and/or distractions, transform negative thoughts into positive thoughts, generate positive feelings by controlling negative thoughts (97%, 93%, and 93% of the time, respectively) ([Table 3](#)).

Table 3. Caregivers' use of positive thinking skills reported in their online weekly homework.

Positive thinking (PT) skills	No. of caregivers completed the homework	Numbers and % of caregivers describing use of PT skill in their online weekly homework
<u>T</u>ransform negative thoughts into positive thoughts (week 2)	28	93% (n = 26)
<u>H</u>ighlight positive aspects of the situation (week 2)	28	86% (n = 24)
<u>I</u>nterrupt pessimistic thoughts by relaxation techniques and/or distractions (week 3)	29	97% (n = 28)
<u>N</u>ote the need to practice positive thinking (week 3)	29	93% (n = 27)
<u>K</u>now how to break a problem into smaller part to be manageable (week 4)	27	85% (n = 23)
<u>I</u>nitiate optimistic beliefs with each part of the problem (week 4)	27	69% (n = 22)
<u>N</u>urture ways to challenge pessimistic thoughts (week 5)	27	69% (n = 22)
<u>G</u>enerate positive feelings by controlling negative thoughts (week 6)	27	93% (n = 25)

All caregivers in the intervention group (n = 28) indicated that they were able to learn all parts of the intervention. Three caregivers, however, indicated they have learned the PTT intervention but they felt that they needed more time to help them to apply and retain the skills they have learned. For example, one caregiver said: "Yes. Need more time to make it a more natural response/routine, however". In the same line, one caregiver stated "Yes but not really well enough to be able to apply them". Yet, a third caregiver stated "Yes, but I had a hard time retaining all of them. I think I took away a few helpful suggestions, but did not retain the whole acronym." Another caregiver shared how she was able to get the most of the PTT intervention by creating flash cards and notes "I think so... I took a lot of notes and have read over them several times. I even made flash cards to put up by my work area to remind me."

Caregivers were also asked about what might have helped them to learn the PTT intervention better. Around one third of the sample (n = 8) indicated that nothing more was needed. Examples of the caregivers' comments were "I thought it was really easy and straight forward... no problems learning it"; "nothing"; and "none". Many great suggestions were provided by caregivers. For example, five caregivers indicated that having a transcript, printouts, or a written material would have been helpful. Examples are: "Written text like a book I could study"; "If we were given hard copies, so we have a reference"; and "I think it would have helped to have printouts".

Three caregivers indicated that having more examples might have been helpful. For example, one caregiver stated: "The acronym was helpful. More concrete examples of carrying out the techniques would have been helpful". Other suggestions include; having a webinar style with more interactions and feedback (one caregiver), more time is needed to practice what they have learned (two caregivers), and that they would prefer sitting in live classrooms where they can freely ask questions (two caregivers).

DISCUSSION

This pilot study is the first study to evaluate the implementation fidelity of a positive thinking training intervention to help caregivers of persons with ASD to improve their positive thinking skills, from the perspectives of the ASD caregivers. The intervention focused on developing eight positive thinking capabilities that can help ASD caregivers in many aspects of their day-to-day lives. This study focused on two aspects of intervention fidelity: receipt of the intervention and enactment by intervention recipients, namely caregivers of persons with ASD. Our findings suggest that adequate receipt and enactment fidelity was reflected in improvements in positive thinking skills for caregivers who received the online PTT intervention. It was expected that the increases would be noted if the teaching was done effectively, and the data indicated that those caregivers of persons with ASD in the intervention group were able to learn the positive skills and to change their thinking ([Bosak, Pozehl, & Yates, 2012](#)).

This study is unique in measuring the intervention fidelity from the caregivers' perspectives. In fact, caregivers of persons with ASD in this study provided insightful comments regarding how to improve the intervention. Future research should include a transcript, printouts, or a written material as well as provide more concrete examples as suggested by the caregivers. A webinar with more interactions can also be included in future research. Two caregivers suggested that they would prefer sitting in live classrooms where they can freely ask questions. This highlighted the fact that some caregivers might enjoy more personal interactions. Therefore, a comparative study between the impacts of the online PTT training versus interpersonal PTT intervention is recommended, in which the caregivers can be given the option to join whatever intervention type that could contribute to their learning styles.

Future research among caregivers of persons with ASD should examine the impact of the other three components of intervention fidelity (study design, provider training, and intervention delivery) on receipt and enactment of the PTT intervention to more fully support its reliability

and validity given the fact that these three components are believed to be an outcome of an intervention ([Michie, 2005](#)).

Limitations of the study include the use of convenience sample of ASD caregivers who uses the internet. Therefore, the results can be generalized only to those who use the internet.

Another limitation is the time frame used in this study. In other words, we collected our data within one week post-intervention and because the measure used in this study captures use of positive thinking skills, we might not see significant changes in caregivers' positive thinking because the caregivers might not have the chance to apply what they have learned. This, in fact, was reflected in the caregivers' narrative stating that they needed more time to apply what they have learned. Therefore, future longitudinal studies might be useful in measuring the effects of the PTT intervention over time; after 3 months, 6 months, and after one year to test the effectiveness and the persistence of the PTT intervention to provide a clear picture about the effective time last after the intervention. Indeed, previous similar intervention studies on resourcefulness indicated that effects on outcomes beginning to emerge at 6 weeks post-intervention and maybe not until 12 weeks post-intervention ([Bekhet and Zauszniewski, 2016](#), [Zauszniewski et al., 2007](#), [Zauszniewski et al., 2006](#)).

In general, the findings of this study support the fidelity of the PTT intervention in terms of receipt and enactment for caregivers of persons with ASD. Those who had the training improved in their positive thinking, and the findings thus support moving forward to test the effectiveness of the positive thinking skills training on intervention outcomes such as caregivers' quality of life and continued examination of reinforcement methods.

ACKNOWLEDGMENT

- This research was funded by the 2015 Summer Faculty Fellowship (SFF) ([19072](#)) and a 2015 Regular Research Grant (RRG) Fund awarded to The Principal Investigator, Dr. Abir K. Bekhet.
- Special thanks to media production specialist, Mr. John Blandino, from the instructional media center at Marquette University for creation of the links to secure the voice over PowerPoint presentations.

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