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Promoting the Positive Thinking and Mindfulness Training for Autism Caregiver with Depression

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Abstract

Autism's problematic behaviors and special care needed are large burdens to the family which might result in depression of caregivers. Positive thinking and mindfulness training can release depression. The purposes of this research and development were to 1) study the situation and related factors of depression among autism caregivers 2) develop and evaluate the model of positive thinking and mindfulness training for autism caregivers with depression. The study consisted of 2 phases including Phase I: analyzing situation and related factors of depression among autism caregivers by questioning and interviewing, Phase II: developing the model of positive thinking and mindfulness training for autism caregivers with depression. The quantitative data were analyzed using descriptive statistics, including Wilcoxon signed-rank test; the qualitative data were analyzed using content analysis. The results of Phase I study demonstrated that mothers of children with autism were more likely to suffer from depression than fathers and their ages were 37.54 years (SD = 8.21). Phase II, construction and development of the model of positive thinking and mindfulness training consisted of 7 elements including: 1) optimistic, 2) belief, 3) commitment, 4) mindfulness in everyday life, 5) basic meditation exercise, and 6) meditation exercises. After applying the model, caregivers of children with autism have the average scores of depression lower than before entering the model significantly ($p < .05$). The results of this study indicated that training which promotes the positive thinking and mindfulness in caregivers of children with autism can decrease depression. Further study on this model in other mental health settings is recommended.

Keywords: Caregiver with depression, Children with autism, Mindfulness, Positive thinking

Introductions

Autism is the most severe developmental disability and involves impairments in social interaction such as being aware of other people's feelings and verbal and nonverbal communication (American Psychiatric Association, 2013). Autism prevalence was 13.4 per 1000 (Christensen, et al, 2016). Sensory deficits across multiple modalities (vision, hearing, touch, olfaction, gustation, and multisensory integration) could result in a high economic cost for caregivers (Knapp, Romeo, & Beecham, 2009). Consequently, caregivers of children with autism spectrum disorders (ASD) were at an increased risk for acute and chronic stress when compared to parents of children with other developmental disabilities (DD) and parents of children without disabilities. Most of these caregivers live with their children for full time and almost all (92%) of the caregivers provided care along with their daily activities (Bekhet, 2016).

Depression is one of the most significant potential adverse consequences for caregivers. Researches have shown that caregivers of children

with ASD report depressive symptoms (Al-Farsi, Al-Farsi, Al-Sharbati, & Al-Adawi, 2016) and is associated with negative psychological outcomes including depressive symptoms (Kirby, White, & Baranek, 2015). Moreover, previous studies showed that parents of children with ASD are at higher risk for developing depression than parents of normally developed children (Khanna et al., 2011). In Thailand, the depression prevalence among caregivers of children with autism was 5.9% (Lerthattasilp, Charernboon, Chunsuwan, & Siriumpunkul, 2015). These caregivers were frustrated and disappointed and the intervening course for caregivers with depression for family adaptability was needed (Baker, Seltzer, & Greenberg, 2011). Caregiver should receive some intervention for decreasing depression. Autism caregivers with mental health problems, for instance, are much more likely to get help if psychosocial intervention is available. Bekhet (2016) suggested that mindfulness and positive thinking are generally associated with less depression.

Positive thinking is a cognitive process that creates hopeful images, develops optimistic ideas, finds favorable solutions to problems, makes affirmative decisions, and produces an overall bright outlook on life (Bekhet, & Zauszniewski, 2013). From the study done by Bekhet (2017a), it was mentioned that high depressive cognitions in ASD caregivers were associated with lower positive thinking. Positive cognitions including specific positive thinking patterns were found to have mediating effects on the relationship between caregiver's depressions (Bekhet, 2016) and general mindfulness parenting had significant mediation effects for maternal depression (Jones, Hastings, Totsika, Keane, & Rhule, 2014). A positive thinking training intervention should be designed to teach caregivers of children with ASD to manage their daily stressors, which has the potential of positively impacting their depression. Caregivers of persons with ASD might benefit from a positive thinking training (PTT) intervention to help them cope with the stress of caregiving (Bekhet, 2017a).

A mindfulness-based program may be a good approach. Mindfulness-based programs are based on the Buddhist traditions of mindfulness meditation and can be adjusted to mental health care based on the Western science of psychology. Participants were trained to pay attention to the present moment, on purpose and with a non-judgmental, openhearted, and curious attitude. The training enhanced attention and awareness of experiences such as bodily sensations, feelings, thoughts, and senses. Also, mindfulness practices are taught to cultivate an accepting and compassionate stance toward experiences (Segal et al., 2012). Moreover, mindfulness parenting was found to act as a significant mediator variable for caregivers' depression. These results contribute to evidence that mindfulness may be important in implications for caregiver support (Jones, Hastings, Totsika, Keane, & Rhule, 2014). The study of Ferraioli and Harris (2013) aimed to test effectiveness of mindfulness and skills-based parent training programs for parents of children with autism. The results of the study demonstrated that the program resulted in statistically significant improvement in parental stress, global health outcome measures, and mindfulness scores. However, no significant changes in parental depression outcomes were observed. Despite these benefits for mindfulness, no study examined the effectiveness of mindfulness training on depression for parents of children with ASD. In the present study, therefore, we were interested in developing a model to promote positive thinking and mindfulness for caregivers of children with autism who suffered from depression. The reason for developing positive thinking with mindfulness among caregivers of children with autism is to create more critical thinking for managing their complex lives. Thus, the purposes of this research were: 1) to study the situation and related factors of depression among autism caregivers 2) to develop and evaluate the model of positive thinking and mindfulness

training of autism caregivers with depression.

Objectives

The objectives of this research were to study the situation and related factors of depression among autism caregivers and develop and evaluate the model of positive thinking and mindfulness training of autism caregivers with depression.

Method

The researchers commenced a research and developmental study following ethical approval obtained from the Research Ethics Review Committee, Rajanagarindra Institute of Child Development, Chiang Mai, Thailand. The study was separated into two phases as follows:

Phase I:

Involved the collection of both qualitative and quantitative data. For qualitative data, purposive sampling was used to ensure participants had the experience of the phenomenon in question. A sample size of nine to thirteen participants was aimed for in order to ensure a sufficient quantity of data by adequately exploring caregivers' experiences. Inclusion criteria of participants were: the age range between 20-60 years; staying with the child for at least previous 6 months and; given written informed consent to take part in the study. Participants were recruited through outpatient services at Rajanagarindra Institute of Child Development, Chiang Mai, Thailand. The aim of qualitative data collection was to enable the respondents to share and express their thoughts, feelings, and experiences. Therefore, semi-structured interview was used for enabling participants to describe their experiences in their own words and style. Throughout the data collection period, the interview was broadly unstructured, with an initial open question being asked: "Tell me about your son/daughter with autism" the conversations developed from there, with topics being explored as they were raised by the participant. Prior to beginning the interview, participants filled in a consent form and demographic information form. The interview was administered to each of the respondents on the principle of voluntary participation, and anonymity of the respondents was upheld during data collection. Interviews were conducted at the outpatient services in Rajanagarindra Institute of Child Development, Chiang Mai, Thailand. All interviews were face-to-face, and lasted from 60 to 90 min. Data analysis was used by content analysis.

For quantitative data, two hundred and twenty caregivers of recently-diagnosed children with autism were included. This sample was drawn from families receiving an ASD diagnosis from a physician service in Rajanagarindra Institute of Child Development, Chiang Mai, Thailand. All caregivers of children diagnosed with ASD were asked to assess caregivers' depression of ASD diagnosis. Caregivers were informed that participation, would not impact ongoing or future care in any manner. Caregiver depressive score was assessed by the 9Q-questionnaire for depression, Thai version (Kongsuk al et., 2007). Data analysis was used by descriptive statistics.

Phase II: Involved development and evaluation of the training program.

Part I: Developing the model

The researchers used the information obtained from Phase I to construct the model. Focus group discussion was used in developing the model of positive thinking and mindfulness training program for autism caregivers with depression. The participants were volunteers obtained from a purposive sampling method among caregivers of children with autism, health care providers and experts.

The model is reviewed and approved by five experts having experience in working with children with ASD for considering the content validity, appropriation and feasibility in the application. Prior to the formal intervention

program, a program trial was given to 3 caregivers in order to test the procedure and usability. Some sessions were readjusted according to the findings and suggestions from the experts.

Part II: Evaluating the model

The subjects in this part were between 20 to 60 years of age and were autism caregivers with depression who have received services from the outpatient unit at Rajanagarindra Institute of Child Development, Chiang Mai. A trained nurse, reviewed caregiver's medical records and screened them to determine whether they were eligible. The participants who met the following criteria were invited to participate in this study, (1) being caregivers of child with autism who have been caring an autistic child at least for 6 months, (2) ability to communicate effectively (3) having a depression score obtained from the 9Q-questionnaire for depression, Thai version in the ranging from 7-12 scores, and (4) giving informed consent to participate in the research either in verbal or written form. If any autistic child caregiver with depression met the criteria, he/she was informed about the study and if agreeable, an inform consent was done. The sample size was calculated according to the formula for testing the difference between two means (one-tailed test) (Norman & Streiner, 2008). It yielded a control group and an experimental group of 23 persons with a statistical power = .90 at f =.05, and the significant level at .05.

About the intervention, caregivers with depression were given appointments to participate in the small group program in order to set up goals, sianed the consent from, and arranged baseline assessment enrolling and signing the consent form, and arranged baseline assessment. The researcher implemented the intervention following all set protocols. Follow-up data were collected at the 4th week right after finishing the program.

The research instruments included demographic data questionnaire and the 9Q questionnaire for depression, Thai version (Kongsuk, 2007). Adequate internal validity of it has been demonstrated. Therefore, validity was not replicated in this study. Depression of autism caregiver was individually measured with the 9Q questionnaire for depression which contains 9 items including loss of interests or pleasure, feeling sad, depressed or hopeless, insomnia, hypersomnia, easily fatigued, poor appetite or overeating, feeling bad about self, trouble concentrating on things, moving or speaking so slowly, and thoughts that he/she would be better off dead. Total scores range from 0 (low likelihood of depression) to 27 (high likelihood). They were considered to represent 'without depressed symptoms' (≤ 6 scores), 'low depressed symptoms' (7-12 scores), 'moderate depressed symptoms' (13-18 scores), 'high depressed symptoms' (≥ 19). The internal consistency reliability of 9Q in this study was 0.87.

At the initial appointment, all subjects were given an overview of the study. The researcher explained to the prospective subjects the purposes and procedure of this study and assurance of the voluntary participation and confidentiality of participation. The subjects received a positive thinking and mindfulness training and were asked to complete assessments of depression by using 9Q questionnaire for depression with a score of 7 or higher before starting the intervention implementation. Right after receiving a positive thinking and mindfulness training session of the 4th week, subjects were evaluated to see the effects of the program on depression. The characteristics of the subjects were described by frequency and percentage. Means, standard deviations and Wilcoxon signed-rank test were used to compare the difference of the 9Q scores at each point of measurement. Before Wilcoxon signed-rank test was used, the assumptions for the homogeneity of variance were tested. In this case, the depression was significantly a non-normally distribution by the Kolmogorov-Smirnov ($p < .05$). Thus, it was appropriate to be tested by Wilcoxon signed-rank test.

Results

Phase I:

The results are organized in two sections including qualitative and quantitative data of caregivers of child with ASD as follows:

For qualitative data, the answers of caregivers regarding impact of the diagnosis on caregivers, indicated that most of them have emphasized;

- Caregiver as a grandmother, father, and mother expressed negative feelings when they knew that their children were diagnosed autism.

- finding major changes in family life:"We have gone to some family reside in rural area and go to work for money in urban area. for money, medication, therapies....Parents gave up their work....Moving to another city. They have to seek a good treatment for their children. Therefore they go to health care setting at another city. seeking health care services to treat our child",

- being situational rejection by someone in family: "Mother got depression and father neglects the child",

- having disagreements between spouses: for example: "widen the gap between me and my husband".

- having negative emotions: despair, fear of changes, unhappiness, and helplessness.

A small number of caregivers identified positive aspects including:

- increasing family cohesion, a change in a helpful approach: "the diagnosis has changed us for the better....has made us to see the world with different eyes...it made us to better understand the children with special needs and....found the efforts of those who support each together and from community",

- organizing better knowledge from this syndrome: "We learned more about this syndrome ...learned what autism is...prepared information for caring",

- changing attitude from this syndrome: "We learned more about dealing with problem....and this syndrome...learned what autism is",

- finding survival way: "I went to Buddhist temple for giving food and things for the monk... doing meditation...regulating my way of life such as physical exercise, shopping, visit relative... embracing mindfulness in my mind".

For quantitative data, It was found that the mean age of 221 caregivers of children with autism was 37.54 years (SD = 8.21). Most subjects were female (74.2%), married (80.5%), and 29.0% were educated at the college level. Nearly forty percent of the subjects were vendors. The majoity of them had the family income less than 10,000 baht per month (57.0%). Most subjects perceived that their income was not sufficient (69.0%). About 43.9% were mothers About 43.9% were mothers who had been the primary caregiver for less than 3 years being a caregiver. Depression as measured by 9Q was found in 78 caregivers (35.2%). Fathers of children with autism were less likely to suffer from depression than mothers.

Phase II:

Part I: Developing the model

For this step, the positive thinking and mindfulness training consisted of 7 sessions, divided into two parts. The first part, positive thinking part which lasted 45-60 minutes for each session. There are three sessions including optimistic thinking training, belief training and commitment initiative training.The second part, mindfulness training part consisted of four sessions including mindfulness in everyday life, basic meditation exercise, meditation exercises and the last session was putting all six items together. The program developed the ability to face with and overcome obstacles among caregivers as follows.

1. Optimistic thinking trained caregivers to recognize the cause for optimism, learn to see another side of problems and view crises and difficulties in life as challenges that provide an opportunity for creating readiness to perseverance to reach desired outcome goal. Optimism has a positive correlation with the ability to survive and to overcome obstacles.

2. Belief trained caregivers to have trust in their abilities and potential. They believed in positive thinking when encountering obstacles of life or crisis and can fight and overcome possible barriers. The locus was the belief that with their abilities and potential successes, failures or possibilities were created.

3. Commitment initiative is one element of positive thinking. Researchers have applied the model to set the participant's life goals and strive to reach their destination status.

4. Mindfulness in everyday life: being able to see old information in new ways, having an awareness of multiple perspectives, avoiding premature cognitive commitment, understanding mindfulness and mindlessness, appreciating the positive aspects of mindlessness.

5. Basic meditation exercise: mindfulness is having the experience without thoughts, meditation on mindful breathing, conscious returning of attention to the breath when the mind wanders away.

6. Meditation exercises: body scan, being in the present moment, loving kindness, a beginner's mind, and letting go

7. Putting them all together: application of mindfulness in the family life, especially in parent–child interactions, overcoming history of mindless parenting practices and freeing the spirit within, being in the present moment with the autistic child, being loving, kind, compassionate and interacting with wisdom

The seven elements encouraged autism caregivers with depression to have the abilities for managing and overcoming obstacles. The model based on the science of psychology and Buddhist perspectives. The researchers concluded that these two concepts are encouraged in order to cope with the problem in a positive way which will decrease depression.

Part II: Evaluating the model

In implementing the model for evaluation, a technical group process with positive thinking and mindfulness methods were used for assisting the training model. Caregivers were ready to cooperate in solving the problems and accepted suggestions in the friendly atmosphere in group activities. The results found that the mean age was 38.93 years (SD = 12.60). Most subjects were female (69.6%), married (74.0%), and 43.6% were educated at the high school level. Nearly forty percent were vendors. The majority of them had personal income less than 3,000 baht per month (39.1%). Most subjects perceived that their income was not sufficient (65.1%). About 52.2% were mothers and had four to six years being a caregiver (Table 1).

Table 1: Demographic Variables of Autism Caregiver with Depression (N=23)

Demographic characteristics	Number	Percentage
Age (years)		
21-30	7	30.4
31-40	5	21.8
41-50	6	26.0
> 50	5	21.8
Mean (SD)	38.93(12.60)	
Gender		
Male	7	30.4
Female	16	69.6

Demographic characteristics	Number	Percentage
Marital status		
Married	17	74.0
Widow	6	26.0
Education		
Primary school	7	30.4
High school	10	43.6
College	6	26.0
Occupation		
Out of work	8	34.9
Office staff	6	26.0
Vendor	9	39.1
Personal income		
1,001-3,000	9	39.1
3,001-6,000	7	30.4
> 6,000	7	30.4
Adequacy of income		
Adequate	8	34.9
Inadequate	15	65.1
Relation to child		
Father	5	21.8
Mother	12	52.2
Grand mother	6	26.0
Time as caregiver (years)		
1-3	7	30.4
4-6	12	52.2
> 6	4	17.4

Considering depression scores for autism caregivers after attending the program, it was found that depression was decreased (Table 2). When the mean depression scores were compared by Wilcoxon signed-rank test, as shown in Table 2 , it was found that there was a significant difference at the 4^{th} week of participation ($p<.05$).

Table 2 : Comparison of Depression of Autism Caregivers at the Baseline, and the 4th Week

Score	Before			After			Z
	Mean	SD	Level	Mean	SD	Level	
Depression	8.07	1.163	Mild depression	3.73	1.335	No depression	-2.809*

*P≤ .05

Discussion

This current study is to promote a positive thinking and mindfulness training program to help autism caregivers of children with ASD to reduce their depression. The intervention focused on developing a seven session program that can help autism caregivers. This study focused on two phases: phase I to study the situation and related factors of depression among autism caregivers. Phase II to develop and evaluate the model of positive thinking and mindfulness training program for autism caregivers with depression consisted of part I: developing the model and part II: evaluating the model.

For phase I

Findings from the current study suggested that depression was found in 78 (35.2%) caregivers. Similar studies conducted in Saudi Arabia concluded that the mean depression scores were significantly higher among cases compared with controls (Almansour et al., 2013). Moreover, mothers of children with autism were more suffer from depression than fathers. These results are in accordance with other international research studies (Al-Towairqi, et al., 2015). Moreover, this study found that caregivers with depression scores had financial problems. These studies confirm that mothers of children with ASD have given up their careers in order to ensure the medical and educational services necessary (Montes & Halterman, 2008). As Piovesan et al. (2015) suggested that depressed mothers were also more likely to report a more negative impact on their financial situation, which was found to be triggered mostly by financial problems (Koydemira & Tosun, 2009) and other family–environment stressors, such as income (Weitlauf et al., 2014). Family support was associated with increased optimism that, in turn, predicted higher levels of positive maternal outcomes and lower levels of negative maternal outcomes. In addition, partner and friend supports were directly associated with maternal outcomes (Ekas, Lickenbrock, & Whitman, 2010).

Our study found that some participants reported experiencing negative aspects such as disappointment, guilt, low self-esteem. Previous studies also have shown a high risk of depression among caregivers of children with autism, which are indicators of a high need for positive thinking, among individuals with low positive thinking (Bekhet, 2016).

For phase II

For developing the model, our research results demonstrated that the model of positive thinking and mindfulness training program for autism caregivers with depression could reduce depression score. caregivers received guideline for preparing method to improve positive thinking and mindfulness on seven sessions. The current study, researchers proposed guidelines for establishing the model as a protocol of promoting positive thought among autism caregivers as follow; 1) health care provider training should include offering – suggesting this practice to autism caregivers for dealing with depression. 2) in implementing this model, health care providers

should add some activities in the model including listen to a song in the preparation before performing the procedure and 3) although this model is based from the Buddhist perspective, the model is appropriate for all religions.

For positive thinking part, our study showed that one session on family support in improving positive thinking is needed. Given that family support was associated with increased optimism (Ekas, Lickenbrock, & Whitman, 2010) and coping through family optimism was most helpful. Moreover, positive thinking skills include transforming negative thoughts into positive thoughts, highlighting positive aspects of the situation, interrupting pessimistic thoughts by using relaxation techniques and distraction, practicing positive thinking, breaking a problem into smaller parts, initiating optimistic beliefs with each part of the problem, and generating positive feelings by controlling negative thoughts (Bekhet & Zauszniewski, 2013). These findings mentioned that the skills most frequently described were: interrupt pessimistic thoughts by relaxation techniques and/or distractions, transform negative thoughts into positive thoughts, and generate positive feelings by controlling negative thoughts (Bekhet, 2017b) and some caregivers may experience a more positive perspective during difficult periods. It was expected that those caregivers with depression in the intervention group were able to learn the positive skills and to change their thinking (Bekhet, 2016).

Mindfulness practice appears to have a positive influence on the well-being of individuals who are parents of children with ASD through both direct (e.g., by lowering their own individual stress) and indirect (e.g., by decreasing child problem behaviors) pathways. These positive influences may have a particularly salient impact because mindfulness techniques learned in one setting appear to transfer to other settings. As parents of children with ASD report experiencing comparatively lower emotional well-being because of their own stress levels and their child's challenges, mindfulness techniques may offer a way to address those concerns (Bluth et al., 2013). Practicing mindfulness results in a significant improvement for emotional well-being (Hofmann et al., 2010). Especially, mothers in mindfulness-based stress reduction These mentioned that autism's caregiver who participated in mindfulness training reported significantly less depression.

For evaluation, caregivers of versus positive adult development had greater improvements in depression (Dykens et al., 2014). children with autism participating a mindfulness and positive thinking training model had a significant decrement of the depression average score at a level of .05. This is consistent with studies of Ridderinkhof et al. (2017) which studied the effects of mindfulness and positive program to reduce depression in autism parents with depression. which was found that depression scores of the experimental group were significantly lower than before entering the program at a level .05. This result demonstrated that this program based positive thinking and mindfulness could change thoughts and behaviors among autism caregivers with depression.

Suggestions

The researchers suggested for further research as follows: 1) there should be a comparative study of the model in the experimental study for testing the effects of the positive thinking and mindfulness training program on anxiety, caregiver burden and emotional intelligence (EQ), and 2) the further study should be conducted in another group of caregivers including children with attention deficit hyperactivity disorder and learning disability.

Conclusion

In conclusion, the present study confirmed that a mindfulness and positive thinking training program could reduce depression among caregivers of children with autism. Further studies are suggested. To maximize the intervention outcome and to alleviate the caregiver depression, health care providers with their team such as family, peers, community leaders, and other decision makers should be aware of caregiver's feelings, such as guilt or low self-efficacy to manage life. This study also has revealed that mothers of children with ASD are suffering from depression more than fathers. Being proactive to help caregivers through challenges and help them to develop hardiness, facilitates improved outcomes in overcoming the challenges related to caregiving a child with autism.

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