

UNIVERSITI PUTRA MALAYSIA

EFFECTIVENESS OF AN EDUCATIONAL PROGRAM TO REDUCE PARENTING STRESS AND IMPROVE COPING MECHANISM AMONG PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN JORDAN

AL-ORAN HAYTHAM MOHAMMAD ABD EL-SALAM



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AL-ORAN HAYTHAM MOHAMMAD ABD EL-SALAM

Thesis Submitted to the School of Graduate Studies, Universiti Putra Malaysia, in Fulfilment of the Requirements for the Degree of Doctor of Philosophy

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DEDICATION

To my father and mother
For their remarkable patience, love and endless support to me as always.

To my siblings
For their supports, encouragement, and motivation to me.

To my great supervisor, Associate Professor Dr.Lee Khuan For her valuable guidance, encouragement, and kind help.



Abstract of thesis presented to the Senate of Universiti Putra Malaysia in fulfilment of the requirement for the degree of Doctor of Philosophy

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By

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Chair : Associate Professor Lee Khuan, PHD Faculty : Medicine and Health Sciences

Parents of children with Autism Spectrum Disorder are prompt to frustration and anxiety due to different stressors and demands over time. This needs to be prioritized in healthcare strategies to maintain the health well-being of parents and to enhance their ability to cope with stress.

The general objective of this study was to develop, implement, and evaluate the effectiveness of the educational program on the parenting stress (including parental distress, parent-child dysfunctional interaction and difficulty of the child) and the coping mechanism (including problem-focused coping and emotion-focused coping) among parents of children with Autism Spectrum Disorder in Amman, Jordan.

A single-blinded, cluster randomized controlled trial was conducted to compare the intervention group versus an active control group. A total of 211 eligible parents were included in this study. Chi-square test and Fisher's exact test (for categorical data) and independent t-test (for continuous data) were used to assess equivalence between the intervention and control groups at the baseline. Repeated Measures MANOVA was conducted on the parenting stress and the coping mechanism.

The mean age of participants was 35.8 years (SD = 4.6), 48.3 % were fathers; while 51.7 % were mothers and they were Muslims (100%). The majority of them were married (97.2 %), employed (71.6 %) with Bachelor's education (44.5%). There were no significant differences in the socio-demographic (p-value < .05) and dependent variables between the intervention and control groups before the intervention (p-value < .05). There were significant main effects for the group (p = .038, p = .002, p < .001), time (p < .001, p < .001, p < .001) and group by time interaction (p < .001, p < .00

.001) for the parent distress, the difficult child and problem-focused coping respectively. The analysis indicated a significant effect of time on the parent-child dysfunctional interaction and emotion-focused coping (p < .00, p < .001) and interaction between the group and time (p < .001, p < .001), but not for the group (p = .250, p = .140).

This study provided empirical support for the effectiveness and feasibility of the educational program in reducing parenting stress and improving the coping mechanism and should be encouraged for its application in the additional setting and studied further for its effectiveness.



Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia sebagai memenuhi keperluan untuk Ijazah Doktor Falsafah

KEBERKESANAN INTERVENSI PROGRAM PENDIDIKAN PADA MENGURANGKAN KELESAHAN IBUBAPA DAN MENINGKATKAN MEKANISME MENGATSI KELESAHAN DIANTARA KALANGAN IBUBAPA PADA KANAK-KANAK DENGAN GANGGUAN AUTISME SPEKTRUM DI, JORDAN

Oleh

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Ibu bapa kanak-kanak dengan Autism Spectrum Disorder cepat kecewa dan cemas kerana tekanan dan permintaan yang berbeza dari masa ke masa. Ini perlu diutamakan dalam strategi penjagaan kesihatan untuk menjaga kesejahteraan kesihatan orang tua dan meningkatkan kemampuan mereka untuk mengatasi tekanan.

Objektif umum kajian ini adalah untuk mengembangkan, melaksanakan, dan menilai keberkesanan program pendidikan terhadap tekanan keibubapaan (termasuk tekanan ibu bapa, interaksi disfungsi ibu bapa-anak dan kesukaran anak) dan mekanisme penanganan (termasuk masalah- penumpuan berfokus dan penanganan berfokus emosi) di kalangan ibu bapa kanak-kanak dengan Autism Spectrum Disorder di Amman, Jordan.

Satu percubaan terkawal rawak tunggal yang dibutakan dilakukan untuk membandingkan kumpulan intervensi berbanding kumpulan kawalan aktif. Sebanyak 211 ibu bapa yang layak dimasukkan dalam kajian ini. Uji Chi-square dan ujian tepat Fisher (untuk data kategorik) dan ujian-t bebas (untuk data berterusan) digunakan untuk menilai kesetaraan antara kumpulan intervensi dan kumpulan kawalan di garis dasar. Langkah Berulang MANOVA dilakukan terhadap tekanan keibubapaan dan mekanisme penanganan.

Umur rata-rata peserta adalah 35.8 tahun (SD = 4.6), 48.3% adalah bapa; sementara 51.7% adalah ibu dan mereka beragama Islam (100%). Majoriti dari mereka berkahwin (97.2%), bekerja (71.6%) dengan pendidikan Sarjana (44.5%). Tidak terdapat perbezaan yang signifikan dalam sosio-demografi (p-value <.05) dan pemboleh ubah

bersandar antara intervensi dan kumpulan kawalan sebelum intervensi (p-value <.05). Terdapat kesan utama yang signifikan bagi kumpulan (p = .038, p = .002, p <.001), masa (p <.001, p <.001, p <.001) dan kumpulan mengikut interaksi masa (p <.001, p <.001, p <.001) untuk kesukaran ibu bapa, anak yang sukar dan untuk mengatasi masalah. Analisis menunjukkan kesan masa yang signifikan terhadap interaksi disfungsi ibu bapa-anak dan mengatasi fokus emosi (p <.001, p < .001) dan interaksi antara kumpulan dan masa (p <.001, p < .001), tetapi tidak untuk kumpulan (p = .250, p = .140).

Kajian ini memberikan sokongan empirikal untuk keberkesanan dan kelayakan program pendidikan dalam mengurangkan tekanan keibubapaan dan memperbaiki mekanisme penanganan dan harus didorong untuk diterapkan dalam pengaturan tambahan dan dikaji lebih lanjut untuk keberkesanannya.



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This thesis was submitted to the Senate of Universiti Putra Malaysia and has been accepted as fulfilment of the requirement for the degree of Doctor of Philosophy. The members of the Supervisory Committee were as follows:

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LIST OF ABBREVIATIONS

ASD Autism Spectrum Disorder

APA American Psychiatric Association

CDC The Centers for Disease Control and Prevention

CBT Cognitive Behavior Therapy

MBI Mindfulness Based Intervention

PD Parental Distress

PCDI Parent-Child Dysfunctional Interaction

DC Difficulty of the Child

CBT Cognitive Behavior Therapy

MBI Mindfulness Based Intervention

DSM The Diagnostic and Statistical Manual of Mental Disorders

PSI-SF Parenting Stress Index-short form PSI-SF

JMOH Jordanian Ministry of Health

MOH Ministry of Health

RMS Royal Medical Services

JUH Jordan University Hospital

KAH King Abdullah Hospital

CHIP Civil Health Insurance Program

UHs University Hospitals

JUST Jordan University of Science and Technology

UNRWA The United Nation Relief and Works Agency

WHO World Health Organization

KHCC The King Hussein Cancer Center

NCDEG The National Centre for Diabetes, Endocrinology, and Genetics

JMOSD Jordanian Ministry of Social Development

NINDS National Institute of Neurological Disorders and Stroke

QRS Questionnaire on Resources and Stress

PSS Parental stress scale

FAS Fetal Alcohol Syndrome

FSCQ-A The Family Stress and Coping Questionnaire

CARS-P Childhood Autism Rating Scale-Parent Version

WCC-R Ways of Coping Checklist-Revised

CHIP Coping Health Inventory for Parents

CSI Coping Strategy Indicator

CSG Coping Style Questionnaire

DEFF Design Effect

PI Principle investigator

RA Research assistants

ITT Intention to Treat

SPSS Statistical Package for Social Science

SD Standard Deviation

M Mean

CHAPTER 1

INTRODUCTION

1.1 Background of the Study

Children's health and well-being are inextricably linked to their parents' physical, emotional, and psychological status. According to Keen, Couzens, Muspratt, and Rodger (2010), maintaining the health and well-being of parents is the precondition in providing optimal care to their children with Autism Spectrum Disorder (ASD). ASD is defined as one of the neurological developmental disorders with moderate to severe impairments in social interactions, communication, and cognitive development and repetitive and restricted behaviors (American Psychiatric Association [APA], 2013). Besides, ASD is described as a group of disorders that includes autism or autistic disorder, Asperger syndrome, and pervasive developmental disorder. Among these, autism or autistic disorder is the most common type of ASD (APA, 2013). The incidence of ASD varies markedly between countries. The Centers for Disease Control and Prevention (CDC) estimates that one in 68 children under eight years old suffer from autism. This new estimate is approximately 30 % higher than the previous estimate in 2012, which was approximately one in 88 children. The incidence rate of ASD in males has been five times higher than females, which was one in 42 boys versus one in 189 girls (CDC, 2016). In Jordan, 12,111 ASD cases have been reported (CDC, 2016).

Notably, children diagnosed with ASD are having difficulties in many aspects of their lives, which include social interaction, behavior, communication, and language (Bluth, Roberson, Billen, & Sams, 2013; Maskey, Warnell, Parr, LeCouteur, & McConachie, 2013). Therefore, it is a challenge for children with ASD in behavior management, communication, and social relationship establishment with their parents and others (Al-Khalaf, Dempsey, & Dally, 2014; Ede et al., 2020). There is no doubt that the core characteristics of ASD are behavioral problems and socio-communication skill deficits, which lead to significant stress in families with these children (Miranda, Mira, Berenguer, Rosello, & Baixauli, 2019; Shepherd, Landon, Taylor, & Goedeke, 2018; Sim, Cordier, Vaz, Netto, & Falkmer, 2017). Invariably, parents are usually the first to notice the developmental differences in their children with ASD (Benson &Karlof ,2009). With that being said, parents who have a child with ASD are often more confused and stressful due to unique stressors and demands over the time (Keenan, Newman, Gray, & Rinehart, 2016; Manan, Amit, Said, & Ahmad, 2018; Zaidman-Zait et al., 2017). The amount of literature on parenting stress is increasing (Bohadana, Morrissey, & Paynter, 2019; Everly & Lating, 2002; Rao & Beidel, 2009). Everly and Lating (2002) defined parenting stress as "a complex construct that involves behavioral, cognitive, and affective components, combination of child and parent characteristics, and family situational components as they relate to the person's appraisal on his or her role as a parent". Besides, Rao

and Beidel (2009) described parenting stress as the strains and pressures experienced when performing care-related tasks for one's child. Therefore, parenting stress is a common condition that has considerable negative impacts on the physical and mental health of parents of children with ASD (Kakkar, & Srivastava, 2017; Kausar, Akram, Dawood, & Ahmad, 2018; Lloyd, Osborne, & Reed, 2019). A considerable amount of literature compared the parenting stress between the parents of children with ASD and the parents of children with other types of developmental disabilities. These studies compared the overall measure of stress between the parents of children with ASD with the parents of children with Down syndrome (Griffith et al., 2010; Pisula, 2007) or those diagnosed with intellectual disability and developmental delay (Estes et al., 2009; Estes et al., 2013; Sinha et al., 2016; Tomanek et al., 2004) or those diagnosed with typical development (Brobst, Clopton, & Hendrick, 2009; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Mcstay Dissanayake, Scheeren, Koot, & Begeer, 2014; Rao & Beidel, 2009).

These extensive studies examined the factors associated with the high level of stress among parents of children with ASD. Some have found that the parent's gender was strongly associated with the high level of stress (Dabrowska & Pisula 2010; Dardas, 2014; Hastings, 2003; Jones et al., 2013; Rivard et al., 2014; Samadi & McConkey, 2014; Sinha et al., 2016; Soltanifar et al., 2015; Tehee et al., 2009). Further studies suggested that parenting stress is associated with younger parents and younger male child (Dardas & Ahmad, 2014a; Derguy, M'Bailara, Michel, Roux, & Bouvard, 2016; Duarte et al., 2005; Koegel et al., 1992; Sinha et al., 2016; Tehee et al., 2009). Also, studies reported that parents were experiencing a higher level of stress in the period right after the diagnostic given (Dardas & Ahmad 2014a; Fleischmann, 2004; Hastings & Johnson, 2001). Studies also reported that parents with lower education levels and monthly income were experiencing a higher level of stress (Benson, 2006; Dardas Ahmad, 2014a; Phetrasuwan & Shandor Miles, 2009; Samadi & McConkey, 2014; Wang et al., 2013). Furthermore, previous studies reported that high level of parenting stress was associated with other factors such as child behavioral problems (Kasperzack et al.,2020; Siu et al.,2019) and lack of professional and social support (Kakkar, & Srivastava, 2017; Rivard, Terroux, Parent-Boursier, & Mercier, 2014; Sim et al., 2017).

Coping with a stressful situation is challenging (Dardas & Ahmad, 2015). According to Lazaras and Folkman (1984), coping refers to the behavioral and cognitive abilities to manage and deal with one's internal and external demands in any stressful situation. In this regard, coping plays a crucial role in mastering, reducing, or tolerating stress, as well as determining whether a stressful event is an adaptive or maladaptive process (Brown et al., 2020; Lyons, Leon, Phelps, & Dunleavy, 2010). Throughout the process, parents will develop a coping mechanism, which is one of the essential methods that allow them to deal with different stressful situations effectively and have better psychological well-being (Luque Salas, Yáñez Rodríguez, Tabernero Urbieta, & Cuadrado, 2017; Lyons et al .,2010; Miranda et al .,2019). The coping mechanisms that usually used by parents when dealing with their ASD children include family support, friends, social support group, service providers, advocacy and religion (Lai, Goh, Oei, &

Sung, 2015; Siah & Tan, 2016). Furthermore, a parent's ability to deal with a high-stress level depends on the effectiveness and quantity of the coping mechanism they employ in managing the demands of the stressors associated with a child with ASD (Mostafa, 2019; Zablotsky, Bradshaw, & Stuart, 2013).

In light of this, the stress and coping theory by Lazarus and Folkman (1984) has been supporting and guiding the stress and coping mechanism literature over the past 25 years. According to Lazarus and Folkman (1984), stress is the reciprocal, bi-directional relationship between an individual and the environment, which is appraised as potential hazards that threaten to harm or challenge the individual. Also, the authors proposed that the cognitive appraisal of a stressor involves both primary and secondary appraisals, which occur virtually at the same time and interact to determine the significance and meaning of events with regards to wellbeing. The primary appraisal refers to the consideration of an individual on the significance of a situation concerning personal values, beliefs, and situational intentions, whereas secondary appraisal refers to a process of cognitive evaluation, which focuses on minimizing harm or maximizing gains through coping responses (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) suggested that a coping mechanism could be problem-focused coping or emotion-focused coping. Problem-focused coping involves identifying the source of the stress and implementing strategies to eliminate or change the stressor. While emotionfocused coping deals more with changing the emotions associated with the stressors.

Without proper support, parents of children with ASD may experience a higher level of stress (Kar, Mukherjee, Goswami, Biswas, & Bhattacharyya, 2020). Therefore, parents who experience a high level of stress require strategies and skills to reduce their stress and improve their coping mechanism (Al-Khalaf et al., 2014). One of the ways to support parents of children with ASD is through educational programs, which assist parents in their roles as primary caregivers (Al-Khalaf et al., 2014; Hemdi & Daley, 2017). Educational programs for parents of children with ASD have become an effective way to educate, train, and support parents in developing successful strategies and skills to manage their children's behaviors (Al-Khalaf et al., 2014; D'Elia et al., 2014; Steiner, Koegel, Koegel, & Ence, 2012). Multi-intervention strategies are commonly used. These strategies include lectures on specific topics such as understanding on ASD definition, characteristics, causes, and diagnosis, communication and social difficulties in children with ASD, principles of managing behaviors, available services, strategies to promote social communication skills and managing parenting stress, and relaxation techniques (Al-Khalaf et al., 2014; Steiner et al., 2012).

Accordingly, educational programs have been developed for parents of children with ASD to provide specialist knowledge and new skills to improve the parent's well-being, reduce parental distress, and increase parent's efficiency and competency (Keen et al., 2010). Furthermore, educational programs also emphasize the importance of coping skills, which maximize the support from coping mechanism in reducing parenting stress. Therefore, adopting helpful coping mechanisms and available support tend to mediate parenting stress and

enhance parent's capability in overcoming the negative consequences of stress (Wang et al., 2013; Zaidman-Zait et al., 2018). To date, studies on educational programs suggested that the involvement of parents of children with ASD in the intervention strategies implementation will help their children to improve their communication skills and social interaction development (Kasari, Gulsrud, Paparella, Hellemann, & Berry, 2015; Steiner et al., 2012). In addition, educational programs are the least expensive and less time-consuming option that can be administered by a non-specialist professional compared to other intervention approaches in reducing parenting stress and improving coping mechanisms such as Cognitive Behavior Therapy (CBT) and Mindfulness-Based Interventions (MBI). Specifically, this study aimed to develop, implement, and evaluate the effectiveness of the educational program among the parents of children with ASD by comparing the scores of the parenting stress and the coping mechanism in the intervention and control groups at the baseline, post-intervention, and two-months follow-up assessments in Amman, Jordan.

1.2 Problem Statement

Caring for an ill child imposes stress on all the family members, especially in the case of ASD, which is considered as one of the most complex neuro-cognitive developmental disorders that last through an individual life and associated with all races and ethnic groups (Dardas, 2014; Kar et al., 2020: Karst & Van Hecke, 2012). Children with ASD face daily challenges in multiple domains of their lives, including social, communication interaction and behavioral problems that may eventually affect parents psychologically (Hutchison, Feder, Abar, &Winsler, 2016; Kar et al., 2020; Oti-Boadi, Dankyi, & Kwakye-Nuako, 2020). Recently, several studies have cited ASD disorder contribute to persistent negative psychological impacts such as parenting stress (Chakraborty, & Ghosh, 2019; Da Paz & Wallander, 2017; Kiani et al., 2019; McRae, Stoppelbein, O'Kelley, Fite, & Greening, 2019). Previously, parents of children with ASD have been reported to have poorer psychological outcomes (Huang et al. 2014; Mori et al. 2009; Tonge, Brereton, Kiomall, Mackinnon, & Rinehart, 2014). They have been documented to experience a higher level of parenting stress (e.g., Dabrowska & Pisula, 2010; Estes et al., 2013; Griffith, Hastings, Nash, & Hill, 2010; Schieve et al., 2011; Silva & Schalock, 2012; Sinha, Verma, & Hershe, 2016), compared to parents of children with other developmental disabilities such as Down syndrome and intellectual disability.

Child characteristics such as impairments of social-communication interaction and behavior problems have been documented to impact the psychological health wellbeing and coping mechanism of parents of children with ASD (Hu, Han, Bai, & Gao, 2019; Kenny & Corkin, 2011; McRae et L., 2019; Phetrasuwan & Miles, 2009; Wang et al. 2011). Parents of children with ASD use a range of coping resources and mechanisms when faced with parenting stress (Hall and Graff 2011; Hastings et al. 2005; Luong et al. 2009; Yazkan, Lus, & Erensoy, 2019). A considerable amount of literature has been published on the coping mechanism. These studies highlighted that parents of children with ASD used support from social groups to reduce the level of stress and improve the coping mechanism (Cappe, Wolff, Bobet, & Adrien, 2011; Ludlow, Skelly, & Rohleder, 2012).

Johnson, Frenn, Feetham, and Simpson (2011) supported that this kind of support is one of the most appropriate and important methods for reducing stress suffered by the parents of children with ASD and improving the wellbeing of parents. This suggests that parents who experience a high level of parenting stress require strategies and skills to manage their level of stress levels, as well as strategies to improve the coping mechanism. Hence, parents of children with ASD adapt well to parenting stress is a significant public health issue that demands attention from healthcare professionals. The nature of the ASD and treatment set parents on the emotional and physical stressor (McStay et al., 2014). Therefore, diagnosed a child with ASD affect whole family responses to changing for the uncertainty of the treatment outcomes, fear from child growth and development, which puts parents in many challenges to face these stressful events and maintained family integration and stability (McStay et al., 2014). In Jordan, parents of children with ASD have several challenges that may negatively impact their wellbeing. The main challenges include the lack of social support and the stigma towards people with developmental disabilities in the Jordanian society (Al-Khalaf et al., 2014; Jabery et al., 2014). Despite the recognition that ASD direct impact on health wellbeing of parents, very little attention paid to supporting parents of children with ASD in Jordan.

Currently, some studies on the educational program pointed out that parental involvement in behavioral management education and the development of particular parenting skills may reduce parenting stress and improve the coping mechanism (Bendixen et al., 2011; Hemdi & Daley 2017; Tonge et al., 2014). Implicatively, the effectiveness of educational programs has been proven in reducing parenting stress and improving the coping mechanisms; it can thus be considered as a potential treatment approach in helping parents of children with ASD. Moreover, the parent education program has been empirically investigated as time and cost-effective intervention method for encouraging parents to improve problematic child behaviors and to promote social interaction skills (Bendixen et al., 2014). The use of educational programs for parents of children with ASD has been extended with good outcomes. It is repeatedly used to reduce parenting stress (Bendixen et al., 2014; Chiang, 2014; Hemdi & Daley, 2017; Keen et al., 2010; Sarabi Jamab et al., 2012; Tellegen & Sanders, 2014) and improve coping mechanism (Al Khalaf et al., 2014; Ergüner-Tekinalp & Akkök, 2004; Samadi et al., 2013). These findings emphasized that an educational program is an effective intervention to reduce parenting stress and improve the coping mechanism among parents of children with ASD. In general, the effectiveness of educational programs in reducing parenting stress and improving coping mechanism has been well studied in a variety of settings worldwide over the years. Invariably, reducing parenting stress and improving coping mechanism among parents is essential when taking care of their children with ASD (Bozkurt, Uysal, & Düzkaya, 2019).

Despite this, very few randomized controlled trial studies have investigated the effectiveness of an educational program on both parenting stress and coping mechanism as the primary outcomes (Al Khalaf et al., 2014; Ergüner-Tekinalp & Akkök, 2004; Samadi et al., 2013). Also, these studies included very small sample sizes (Al-Khalaf et al., 2014; Bendixen et al., 2011; Ergüner-Tekinalp & Akkök, 2004; Keen et al., 2010; Hemdi & Daley., 2017; Samadi et al., 2013; Sarabi-Jamab et

al., 2012). In Jordan, less attention paid to address the psychological needs of parents of children with ASD, as well as they are a few researchers have been attempted to examine this area and there is a dearth of educational support program studies in Jordan. In addition, the effectiveness of educational programs in reducing parenting stress and improving coping mechanism still a comparatively new intervention approach in Jordan. Only one study attempted to investigate this area and hence, there is a dearth of supportive intervention studies in Jordan (Al-Khalaf et al., 2014). In their study, Al-Khalaf et al. (2014) examined the effects of the education program among ten mothers of preschool-age children with ASD in Jordan. However, this study was limited as it only focused on mothers, applied quasi-design, small sample size, and lack follow-up assessment. Also, the study only provided ASD related information to the mothers but not the coping mechanism modality approaches such as problem-solving skill therapy and relaxation techniques.

As discussed, there is an increasing amount of literature that recognizes the importance of educational programs and provides empirical evidence that intervention approaches can reduce parenting stress and improve coping mechanism. Additionally, it has been more than 15 years that educational program as intervention approaches to reduce parenting stress and improve coping mechanism have been supported in research evidencing. Nevertheless, the results of previous studies have indicated several gaps in the literature. Firstly, the literature review showed a lack of randomized controlled trial studies that focus on the evaluation of the effectiveness of an educational program on parenting stress and coping mechanisms as the main study objectives. Secondly, the majority of the intervention studies only considered the viewpoints of the mothers and lacked empirical studies that involve the views of the fathers. Thirdly, the small sample size was the main limitation of the previous studies. Lastly, there have been lacking studies undertaken in Arabic speaking countries, especially in Jordan. Given gaps in the literature, the objective of this study was to develop, implement, and evaluate the educational program on parenting stress and the coping mechanism among the parents of children with ASD in Amman, Jordan.

1.3 Significance of the Study

This study will have both theoretical and practical contributions.

1.3.1 Theoretical Contributions

Concerning theoretical contributions, firstly, this study has contributed significant knowledge to the field as there is lacking study that uses a cluster randomized controlled trial design to evaluate the effectiveness of an educational program on parenting stress and coping mechanism among parents of children with ASD in Jordan. Therefore, this study could be the starting point to give greater awareness to administrators and policymakers to modify plans, policies, and protocols for future educational programs and supportive care for parents. Secondly, the results of this study provided the baseline information on parenting stress and coping mechanism among Jordanians parents of children with ASD, which may assist

health educators in planning and preparing target and appropriate educational programs. It also serves as a reference for the evaluation of future educational programs by relevant agencies. Besides, the information enables health care providers and planners to structure health organizations in such a way that encourages and maintains supportive care. Thirdly, health care professionals are mainly focusing on children with illnesses and disorders but not the well-being of their parents. Therefore, the education program that developed in this study will benefit the parents by increasing their knowledge and understanding of ASD. Besides, the program empowers them with new strategies and skills that will eventually help them in reducing parenting stress and improving the coping mechanism. Lastly, the findings of this study would be particularly valuable to other researchers in conducting further studies, especially those with mixed methods or qualitative research and other settings.

1.3.2 Practical Contributions

Parents play a significant role in the child's development and growth by being responsible to care for their child, whether the child is healthy or ill. As for practical contributions of this study, firstly, it allows both parents to involve actively in the educational program. It is envisaged that the findings from this study would be useful to enhance the psychological status of both parents of children with ASD in Jordan, which eventually will have positive impacts on the well-being of their children. Secondly, this study helps policymakers to adopt psychological support and treatment as part of the therapeutic strategy. Thirdly, this study facilitates the development of the educational program module in Jordan for Jordanian parents of children with ASD. In addition, this study provides management skills and strategies that help parents in handling their child's ASD symptoms at home and in public settings, which in turn, may reduce parenting stress and improve their coping mechanism. Lastly, this study helps nurses in playing their unique role in the primary health care level, which includes promoting health education, physical, intellectual, and emotional well-being in the context of family and communities. Besides, nurses are also playing a pivotal and critical role as an indicator that reveals the views of parents and their children. In particular, in the recent decade, parent's satisfaction with nurses has been a reliable and valid standard for the quality of care due to the role of nurses as educators, counselors, and researchers in the health care system. In short, this study contributes to the nurses' role in the future by taking part in modifying and delivering educational programs. Moreover, the findings of this study offer a new context of nursing education related to psychological care for parents of children with ASD.

1.4 Research Objectives

1.4.1 General Objective

The overall aim of this study was to develop, implement, and evaluate the effectiveness of the educational program on the parenting stress (including parental distress [PD], parent-child dysfunctional interaction [PCDI], and

difficulty of the child [DC]) and the coping mechanism (including problem-focused coping and emotion-focused coping) among parents of children with ASD in Amman, Jordan.

1.4.2 Specific Objectives

- 1) To compare the baseline socio-demographic characteristics of parents and their children in the intervention and control groups.
- 2) To develop and implement the educational program for parenting stress (PD, PCDI, and DC) and coping mechanism (problem-focused coping and emotion-focused coping) targeting Jordanian parents of children with ASD.
- 3) To determine the mean difference in parenting stress scores (PD, PCDI, and DC) between the intervention and control groups across the three times (baseline, post-intervention and two-months follow-up).
- 4) To determine the mean difference in coping mechanism scores (problem-focused coping and emotion-focused coping) between the intervention and control groups across the three times (baseline, post-intervention and 2-months follow-up assessment).

1.5 Research Questions

- 1) What are the socio-demographic characteristics of the parents and their ASD children in the intervention and control groups at the baseline assessment?
- 2) How can the educational program be developed and implemented for parenting stress (PD, PCDI, and DC) and coping mechanism (problem-focused coping and emotion-focused coping) targeting Jordanian parents of children with ASD?
- 3) Are there any differences in the parenting stress (PD, PCDI, and DC) between the intervention and control groups across the three times (baseline, post-intervention and two-months follow-up)?
- 4) Are there any differences in the coping mechanism (problem-focused coping and emotion-focused coping) between the intervention and control groups across the three times (baseline, post-intervention and two-months follow-up)?

1.6 Research Hypotheses

To examine specific objective #3

RH1a: There would be a significant group effect (intervention vs. control) on the PD

RH1b: There would be a significant time effect (baseline, post-intervention, and two-months follow-up) on the PD.

RH1c: There would be a significant group by time interaction effect on the PD.

RH2a: There would be a significant group effect (intervention vs. control) on the PCDI.

RH2b: There would be a significant time effect (baseline, post-intervention, and two-months follow-up) on the PCDI.

RH2c: There would be a significant group by time interaction effect on the PCDI.

RH3a: There would be a significant group effect (intervention vs. control) on the DC.

RH3b: There would be a significant time effect (baseline, post-intervention, and two-months follow-up) on the DC.

RH3c: There would be a significant group by time interaction effect on the DC.

To examine specific objective #4

RH4a: There would be a significant group effect (intervention vs. control) on the problem-focused coping.

RH4b: There would be a significant time effect (baseline, post-intervention, and two-months follow-up) on the problem-focused coping.

RH4c: There would be a significant group by time interaction effect on the problem-focused coping.

RH5a: There would be a significant group effect (intervention vs. control) on the emotion-focused coping.

RH5b: There would be a significant time effect (baseline, post-intervention, and two-months follow-up) on the emotion-focused coping.

RH5c: There would be a significant group by time interaction effect on the emotion-focused coping.

1.7 Study Variables

The independent variable in this study was the educational program. The educational program was implemented to observe its effects on the parenting stress (PD, PCDI, and DC) and the coping mechanism (problem-focused coping and emotion-focused coping), which were the dependent variables.

1.8 Conceptual Definitions

1.8.1 Educational Program

The educational program is defined as multi-stranded interventions designed to educate and support parents with specialized information on ASD, social, communication, and behavior of their children. Besides, it provides the parental skills and strategies required in managing children's behavior and communication skills (Steiner et al., 2012).

1.8.2 Parenting Stress

Parenting stress is defined as an aversive emotional and psychological response to the demands of being a parent that exceed the complex combination related to the parent, child, and parent-child communications (Abiding, 1995).

1.8.3 Coping Mechanism

A coping mechanism is described as a frequent change in cognitive and behavior efforts to handle external and/or internal demands that are evaluated as demanding or greater than the person resources (Lazarus & Folkman, 1984).

1.8.4 Parents

In this study, Jordanian biological parents are both fathers and mothers of ASD children.

1.8.5 Children with ASD

The Diagnostic and Statistical Manual of Mental Disorders DSM-V was used to assess ASD severity among children based on the impairments in social communication and repetitive and restricted pattern of behaviors (APA, 2013).

1.9 Chapter Summary

Chapter 1 covered a composite of the elements that initiated in the present study. This chapter introduced that parents of children with ASD faced unique challenges, which results in a variety of negative psychological impacts and justified the need for supportive care for improving the parent's health well-being. In addition, this chapter discussed the purpose of the present study, which aimed to evaluate the effectiveness of an educational program on parenting stress and coping mechanism among Jordanian parents of children with ASD. The practical and theoretical contributions of the current study were presented. Additionally, non-directional research hypotheses were outlined. This chapter is ended with the conceptual definitions of variables

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