DEVELOPMENT AND EVALUATION OF A “HeartBEAT” ADOLESCENT TRANSITION PSYCHOEDUCATIONAL PROGRAM ON SELF-MANAGEMENT FOR ADOLESCENTS WITH CONGENITAL HEART DEFECTS

BY

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ABSTRACT

The purpose of the thesis is to develop and evaluate a “HeartBEAT” Adolescent Transition Psychoeducational Program (ATPP) to facilitate self-management skills of adolescents with Congenital Heart Defects (CHD). Based on this purpose of the study, three specific objectives were formed as below: (1) to explore and identify the needs of adolescents with CHD; (2) to design the contents of the “HeartBEAT” Adolescent Transition Psychoeducational Program; and (3) to evaluate the short-term impact of the Adolescent Transition Psychoeducational Program.

The program’s development and evaluation is formative in nature. To achieve these research objectives, the research methods follow Maher’s program evaluation framework (2012) as its research framework.

Research objective one applied qualitative study, interviewed seven adolescents with CHD, six parents and four health care providers. Five main themes of adolescents’ experience and challenges related to (1) emotional/ psychological issues, (2) progress of illness, (3) relationship issues, (4) future preparation, and (5) school and community, were identified.

The findings of research objective two outlined the conceptual framework derived from a shared management model (2000) and Antonovsky’s salutogenic model (1987). Program descriptions were done based on the outline of Frechtling (2007)’s logic model, including goals, rationale, resources, activities and etc. Training manual was formed to ensure the standardization of the practices, and three experts in healthcare sector and psychology field reviewed these documents.

The results of specific research objective three are comprised of the findings of both impact and process evaluations. Fourteen participants were recruited, but only eight were able to complete the program. Looking at the short-term impact of the ATPP, the program had significantly increase self-management knowledge, affectionate support, emotional regulation skills and capacity to identify their life plan. However, their self-management skills were not significantly increased, which might be due to overprotection of the parents and communication issues in healthcare.

On the process of protocol evaluation, four mental health professionals were able to conduct the “HeartBEAT” ATPP more than 90% based on Strategy and Information Checklists. In addition, they have also shared on the challenges in implementing online support groups in the ATPP. Two main themes have emerged, which are the challenges related to participants and challenges related to the usage of technology. These results demonstrate the success of the “HeartBEAT” ATPP in achieving the objectives of this study. The limitations of the study are small sample size, high attrition rate and does not involve participants during qualitative analysis methods. The implications of the study demonstrate the success of the ATPP in achieving the objectives of this study, and the program is affordable, accessible and available.

خلاصة البحث

يهدف البحث إلى تطوير برنامج التأهيل النفسي للمراهقين (ATPP) وتقييمه؛ لتسهيل مهارات الإدارة الذاتية للمراهقين ذوي عيوب القلب الخلقية (CHD)، وعليه؛ تمثَّلت أهداف البحث في استكشاف احتياجات أولئك المراهقين وتحديدها، وتصميم محتويات برنامج التأهيل النفسي لديهم، وتقييم الأثر قصير الأجل لذلك البرنامج تقييمًا تكوينًا، ولتحقيق هذه الأهداف توسَّل الباحث إطار تقييم برنامج ماهر (2000) إطارًا بحثيًّا خاصًّا به، ونهجًا نوعيًّا موضوعيًّا عبر مقابلات مع سبعة مراهقين مع CHD، وستة من الآباء والأمهات، وأربعة من مقدمي الرعاية الصحية، وجرى تحديد خمسة مواضيع رئيسة من تجارب المراهقين وتحدياتهم تتعلق بقضايا عاطفية نفسية، وتقدُّم المرض، وقضايا العلاقات، والإعداد المستقبلي، والمدرسة والمجتمع، وقد أوجزت نتائج الهدف الثاني الإطار النظري المستمد من أنموذج الإدارة المشتركة وأنموذج أنتونوفسكي، مع توصيف للبرنامج بناء على الخطوط العريضة لأنموذج فريختلنج (2007) المنطقي؛ بما في ذلك الأهداف، والأساس المنطقي، والموارد، والنشاطات، وغيرها، وأيضًا تكوين دليل تدريبي لضمان توحيد الممارسات، ثم استعراض هذه الوثائق من ثلاثة خبراء في مجالي الرعاية الصحية وعلم النفس، في حين تألَّفت نتائج الهدف الثالث من نتائج كلٍّ من تقييم الأثر وعمليات التقييم، وشارك في ذلك أربعة عشر مشاركًا، ثمانية منهم فقط تمكنوا من إكمال البرنامج، وبالنظر إلى التأثير قصير الأجل للبرنامج؛ يُلاحظ أنه زاد كثيرًا معرفة الإدارة الذاتية، والدعم الماهر، ومهارات التنظيم العاطفي، والقدرة على تحديد خطة حياتهم، وعلى الرغم من ذلك؛ لم تزد مهاراتهم في الإدارة الذاتية كثيرًا، مما قد يرجع إلى الحماية المفرطة من الآباء والأمهات، وقضايا الاتصال في مجال الرعاية الصحية، أما في خطة تقييم العمليات فتمكَّن أربعة من متخصصي الصحة العقلية من تطبيق البرنامج بنسبة فاقت 90٪؛ استنادًا إلى قوائم مراجعة الإستراتيجية والمعلومات، إضافة إلى أنهم شاركوا في تحديات تنفيذ مجموعات الدعم عبر الشابكة في البرنامج، وقد ظهر موضوعان رئيسان؛ هما: التحديات المتعلقة بالمشاركين، والتحديات المتعلقة باستخدام التقانة، مما يدلُّ على نجاح البرنامج في تحقيق أهداف البحث، فضلاً عنه تسجيل القيود المفروضة على البحث والتوصيات للتحسين في المستقبل.

APPROVAL PAGE

The thesis of Student’s Name has been approved by the following:

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DECLARATION

I hereby declare that this dissertation is the result of my own investigations, except where otherwise stated. I also declare that it has not been previously or concurrently submitted as a whole for any other degrees at IIUM or other institutions.

Tye Sue Kiat

Signature .... Date ....

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CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND OF THE STUDY

Internationally, the prevalence of children born with congenital heart defect (CHD) is around 8 to 10 per 1000. In Malaysia, with the calculation of 500,000 children born per annum, 5000 children are estimated to be born with congenital heart defects every year (Ministry of Health Malaysia, 2007; Pillai, Yoshida, Lawrence, Yamamoto, Reyer, & Hamajima, 2016). Similar with the patterns internationally, the most common Congenital Heart Defects in Malaysia are Ventricular Septal Defects, Parent Arterial Duct and Atrial Septal Defects (Hung, Mohan, Soo, & Ng, 2000; Pillai, Yoshida, Lawrence, Yamamoto, Reyer, & Hamajima, 2016).

In Malaysia, there are 58 hospitals that are able to provide cardiothoracic services. In pediatric cardiology and cardiothoracic service, Institut Jantung Negara (National Heart Institute Malaysia) is the main tertiary hospital. Hospitals such as Penang General Hospital, Sultanah Aminah Hospital, and Sarawak General Hospital also perform surgeries on children with simple CHD (Ministry of Health Malaysia, 2007; Pillai, Yoshida, Lawrence, Yamamoto, Reyer, & Hamajima, 2016).

The mortality rate of patients with CHD was high in the past, especially those with complex heart defects (Moons et al., 2005). However, in recent years the increasing awareness of the illness and advances in imaging have enabled early detection of the illness, thus increasing the likelihood of patients getting proper treatment (Benjamin et al., 2017; Hung et al., 2000; Moons et al., 2005).

Moreover, the development of intensive care, congenital heart surgeries, new procedures, electrophysiological treatment and pharmacology have successfully increased the probability of survival in infants, resulting in a significant rise in the number of infants abled to survive to adolescence. This is even true for adults with CHD (Benjamin et al., 2017; Marelli, Mackie, Ionescu-Ittu, Rahme, & Pilote, 2007; Stoutz & Leventhal, 2009). Such advances in the medical field has sparked hope for the continuously growing number of adolescents and adults with CHD With the continuously growing number of adolescents and adults patients with CHD, which the prevalence of adult patients with CHD has reached 300 per million of adults (Van der, Bouma, Meijboom, & Zwinderman, 2012), there is an increase in interest in their quality of life and issues.

1.1.1 Issues faced by adolescents living with CHD

Moving towards adulthood, adolescents may be expected to go through a period of vulnerability, such as formation of own identity (Pahl & Grady, 2012). On top of that, the adolescent stage is a transition period of shifting responsibility from the caregivers to themselves. With the medical obstacles, these patients need to face various challenges from different aspects, including physical, mental, relationship, lifestyles and healthcare.

Physically, there are patients with moderate and severe CHD who may need to live with symptoms and physical limitations caused by illness or treatments such as surgery. Some common symptoms of having congenital heart defects are fatigue, rapid breathing, dizziness, poor blood circulation, palpitation and others (Brickner, Hillis, & Lange, 2000; Karsenty et al., 2015). For those with severe complications, they need to be hospitalised frequently to manage their symptoms, thus having to adjust their normal life routine in order to receive treatments (Brummett et al., 1998; Karsenty et al., 2015; Rometsch et al., 2018).

Some patients with CHD might develop significant morbidities in the treatment process, such as cardiovascular complications and neurocognitive issues, which result in other surgeries or interventions, restrictions in exercise, the inability to get pregnant and the need to take chronic medications to survive (Nakamura et al., 2018; Pike et al., 2016; Schultz & Wernovsky, 2005).

Emotionally, if the adolescents fail to adapt to the changes derived from an illness, it might generate anxiety, fear and even increase their risk in getting depression (Brummett et al., 1998; DeMaso et al., 2017; Westhoff-Bleck et al., 2016). Having continuously negative feelings, especially hopelessness, might jeorpadise the risk of mortality of patients with cardiovascular diseases (Stern, Dhanda, & Hazuda, 2001). Even though patients with CHD have a high risk of developing mood and anxiety disorders, their emotional health is found to be undertreated and ignored (DeMaso et al., 2017; Kovacs et al., 2009).

Socially, the illness might affect the patients' relationship with family, peers and even romantic partners. For instance, Pahl and Grady (2012) found out that adolescents or young adults face more difficulties to develop and maintain significant relationships. Where interaction with peers is concerned, they often found themselves hindered by their illness, unable to join physical activities such as hiking and camping subsequently they feel left out and excluded by peers (Kendall, Sloper, Lewin, & Parsons, 2003).

With regard to their lifestyle, some adolescents with CHD have difficulty in their education or career (Pahl & Grady, 2012). Although in Malaysia, employment statistic of patients with disabilities and chronic illness conditions are not found. In a study of the US, only 44% of respondents were employed. 67% of those who were not employed wished to work (Blomquist, 2006).

From the perspective of healthcare, adolescents with CHD are in the transition of shifting the services from paediatric to adult management. This transition is often described as random and non-organized, thus often causing patients' non-adherence and difficult behavior. Moreover, if the transfer is sudden and unprepared, the adolescents might interpret the transition as a punishment and rejection (Burstrom, Bratt, Frenckner, Nisell, & Hanseus, 2017; Viner, 2001).

On top of that, as part of the transition to adulthood, adolescents with CHD are also being expected to manage their own health care, including taking their own medication, or even making their own appointment. Unfortunately, if these adolescents are not equipped with good analysis and decision-making skills, emotion management skills and are involved in risk taking behaviours, they are more likely to adhere poorly to medical care, which may eventually lead to poor health outcomes (Pahl & Grady, 2012).

To address and resolve the issues above, particularly health care and lifestyle issues, various studies have suggested the need to have the services of formal Adolescent Transition Program to prevent discontinuity of care, financial or psychology related issues, to meet vocational, educational and other social needs and to promote future health (Hays, 2015; Hergenroeder, 2002; Kovacsa et al., 2012; Moceri et al., 2015; Moons et al., 2009; Sable et al., 2011; Said, Driscoll, & Dearani, 2015). Adolescent Transition Program (ATP) is aimed to optimize adolescents' health, (Blum et al., 1993; Rosen, Blum, Britto, Sawyer, & Siegel, 2003) so that they have greater personal and medical independency and also possess better control over their health (Sable et al., 2011).

1.2 STATEMENT OF PROBLEMS

There are various issues that influence the well-being of individuals with CHD. Issues that would discussed in the sections below include availability of the program and delivery of training, issues in developing and evaluating Adolescent Transition Program that would suit the Malaysian context, and the needs to address adolescents' developmental and mental health issues in implementing the Adolescent Transition Program.

1.2.1 Availability of transition program and delivery of training

Numerous studies have indicated the significance of formal Adolescent Transition Program on handling health care transition process, medical issues such as discontinuity of care, and psychosocial issues such as educational and vocational needs (Hays, 2015; Hergenroeder, 2002; Kovacsa et al., 2012; Moceri et al., 2015; Moons et al., 2009; Sable et al., 2011; Said et al., 2015).

However, scarce research suggest that Adolescent Transition Programs for CHD are not widely available (McPheeters et al., 2014). Even in the United States, only five percent of state mental health administrators from the United States reported the existences of transition services or programs (Hunt & Sharma, 2013). Of those 5 to 50 percent of hospitals and clinics which offer transition programs, some degree of inaccessibility of the program was reported. The public rarely gives attention to adolescent transition issues (Park, Adams, & Irwin, 2011) and some clinics do not even have formal plans to execute the transition from peadiatric to the adult services (McPheeters et al., 2014).

Fourty percent of the respondents in a study by Hunt and Sharma (2013) were not comfortable in dealing with patients with chronic disease of childhood from the onset as they were not familiar with the literature, lacked training and there were other issues as well.

In Malaysia, a majority of Adolescent Health programs are aimed at HIV / AIDS prevention, such as Health without AIDS Program for Adolescents (Jaafar et al., 2013). Before the current project was implemented, there are no other Adolescent Transition programs provided to adolescents with Congenital Heart Disease in Malaysia.

1.2.2 Issues in developing and evaluating ATP

According to existing literature, transition programs, patient's education, psychosocial issues, quality of life and other related studies should be given priority to expand and strengthen the body of knowledge in congenital heart defects (Goossens, Fleck, Canobbio, Harrison, & Moons, 2012). In Malaysia, there is a lack of psychosocial interventions and structured, well-designed, blinded and controlled studies done for adolescents and adults with CHD.

Even at international level where past research proposed and implemented various models of transition, the outcome data of evaluating the effectiveness of the used models of transition and the transition programs are still insufficient (Rosen et al., 2003; Viner, 2001). McPheetars and his colleagues (2014) conducted a literature analysis of transition services, and in spite of identifying numerous literature describing transition programs, they could only identify 24 evaluation studies, and the population were rarely patients with CHD. Goossens et al (2014) corroborated this lack of data when they observed that no past research had been conducted to assess the effectiveness of structured educational programs for adolescents with CHD.

Although a number of health care organizations have proposed transition programs for adolescents with chronic illnesses, many just developed and executed