

**THE DEVELOPMENT AND EVALUATION OF AN
INTERVENTION PROGRAMME FOR ADOLESCENTS
LIVING WITH HIV/AIDS IN MALAYSIA**

BY

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ABSTRACT

United Nations International Children's Emergency Fund (UNICEF) Malaysia has found that adolescents living with HIV/AIDS face several emotional, behavioural and social problems. Based on past literature, the result of these issues has led to a lower well-being in these aspects. Given the lack of studies investigating the issues facing adolescents living with HIV/AIDS in a Malaysian setting, the present study sought to fill this gap in research by carrying out three main studies that relate to the three main objectives of the study: Study 1: identifies the issues facing adolescents living with HIV/AIDS, Study 2: develops an intervention programme for adolescents living with HIV/AIDS and Study 3: evaluates the developed intervention programme for adolescents living with HIV/AIDS. These three studies employed a participatory action research approach (Kloos, 2000). The main participants are 15 Malaysian adolescents with living HIV/AIDS from shelter homes; the personnel of the shelter homes comprising the programme coordinators, staff and volunteers of the shelter homes, recruited via purposive sampling. The identified issues facing adolescents with HIV were used as bases in ascertaining the domains to be included in a culturally-tailored wellness intervention programme designed to suit the Malaysian population of adolescents with HIV. This intervention programme was developed based on the identified issues facing adolescents living with HIV/AIDS and a review of literature of intervention programmes aimed at improving the well-being of adolescents living with HIV/AIDS. This developed and adapted wellness intervention programme was named 'Be Your BEST' (Behavioural, Emotional, Social, Teamwork) and it comprises 3 main modules (Emotional Well-Being Module- Session 1 to 4, Behavioural Well-Being Module- Session 5 to 7, Social Well-Being Module- Session 8 to 10) were mainly aimed at increasing the emotional, behavioural and social well-being of the adolescents. The present study then evaluated the effectiveness of the developed wellness intervention programme through a participatory action research (PAR) approach. This study used a mixed-method approach with qualitative (focus group discussions) and quantitative (experimental design) methods. The effectiveness of the intervention programme was assessed via the use of three measures, namely the BarOn Emotional Quotient Inventory (BarOn EQ-i Youth Version) (Bar-On & Parker, 2000), the Child Behaviour Checklist-Youth Self-Report Form (YSR) (Achenbach, 2001) and the developed and validated scale in the present study, the Content Knowledge of a Wellness Intervention Programme Instrument. Post-intervention results revealed that the developed and adapted wellness intervention programme (Be Your BEST programme) yielded promising results with a 60% decrease in overall behavioural problems and a 100% increase in overall emotional and social well-being among the participants. The highest amount of increase in emotional and social well-being was for the subscales Interpersonal Scale and Stress Management Scale (100% each). This is followed by Intrapersonal Scale, Adaptability Scale and the General Mood Scale (93.33% each) while the highest amount of decrease was the subscales Anxious/depressed subscale (73.33%) and Aggressive behaviour (73.33%), followed by Attention problems (66.67%) and a 60% reduction were for the subscales Withdrawn/depressed, Thought Problems and Other Problems. The smallest reduction among the subscales was for Somatic Complaints, Social Problems and Rule-breaking behaviour (53.33% each). It is hoped that the developed intervention programme will be able to be replicated and

implemented in various organization across the nation to help increase the well-being of other adolescents living with HIV/AIDS.

Keywords: HIV/AIDS, intervention programme, participatory action research, well-being



خلاصة البحث

لقد وجد صندوق الطوارئ الدولي للأطفال التابع للأمم المتحدة (اليونيسف) في ماليزيا أن المراهقين المصابين بفيروس نقص المناعة البشرية/الإيدز يواجهون العديد من المشاكل العاطفية والسلوكية والاجتماعية. بناءً على الدراسات السابقة، لقد أدت نتيجة هذه القضايا إلى تدني مستوى الرفاهية في هذه الجوانب. نظرًا لقلّة الدراسات التي تبحث في القضايا التي تواجه المراهقين المصابين بفيروس نقص المناعة البشرية/الإيدز في بيئة ماليزية، سعت الدراسة الحالية إلى سد هذه الفجوة في البحث من خلال إجراء ثلاث دراسات رئيسية تتعلق بالأهداف الرئيسية الثلاثة للدراسة: الدراسة 1: تحديد القضايا التي تواجه المراهقين المتعاشين مع فيروس نقص المناعة البشرية/الإيدز، الدراسة 2: تطوير برنامج تدخل للمراهقين المتعاشين مع فيروس نقص المناعة البشرية/الإيدز والدراسة 3: وتقييم برنامج التدخل المطور للمراهقين المصابين بفيروس نقص المناعة البشرية/الإيدز. قد استخدمت هذه الدراسات الثلاث منهج البحث التشاركي (Kloos، 2000). وكان المشاركون الرئيسيون هم 15 مراهقًا ماليزيًا مصابًا بفيروس نقص المناعة البشرية/الإيدز من دور الإيواء؛ ويتكون موظفو دور الإيواء من منسقي البرنامج والعاملين والمتطوعين في دور الإيواء، الذين تم تجنيدهم عن طريق اختيار العينات القصدية كما تم توظيف المشكلات المحددة التي تواجه المراهقين المصابين بفيروس نقص المناعة البشرية وصفها أساسًا في التأكد من المجالات التي سيتم تضمينها في برنامج التدخل الصحي للمصمم ثقافيًا ليناسب السكان الماليزيين من المراهقين المصابين بفيروس نقص المناعة البشرية. وتم تطوير برنامج التدخل هذا على أساس القضايا المحددة التي تواجه المراهقين الذين يعيشون مع فيروس نقص المناعة البشرية/الإيدز ومراجعة دراسات برامج التدخل التي تهدف إلى تحسين رفاه المراهقين المصابين بفيروس نقص المناعة البشرية/الإيدز. لقد تم تسمية برنامج التدخل الصحي المطور والمكيف هذا باسم "كن أفضل ما لديك" (السلوكية والعاطفية والاجتماعية والعمل الجماعي) حيث يتألف من 3 وحدات رئيسية (وحدة الرفاهية العاطفية - الجلسة 1 إلى 4، وحدة الرفاهية السلوكية - الجلسة 5 إلى 7، وحدة الرفاه الاجتماعية - الجلسة 8 إلى 10) كما تهدف بشكل أساسي إلى زيادة الرفاهية العاطفية والسلوكية والاجتماعية للمراهقين. وأجرت الدراسة الحالية بعد ذلك فعالية تقييم برنامج التدخل الصحي المطور من خلال نهج البحث العملي التشاركي (PAR). استخدمت هذه الدراسة منهجًا مختلطًا مع الأساليب النوعية (مناقشات في مجموعة التركيز) والكمية (التصميم التجريبي). وتم تقييم فعالية برنامج التدخل من خلال استخدام ثلاثة مقاييس، وهي Bar-On Emotional Quotient Inventory (BarOn EQ-i Youth Version) (Bar-On & Parker, 2000), the Child Behaviour Checklist- Youth Self-Report Form (YSR)

(Achenbach, 2001) والمقياس الذي تم تطويره والتحقق من صحته في هذه الدراسة وهو معرفة المحتوى لأداة برنامج التدخل الصحي. لقد كشفت نتائج ما بعد التدخل أن برنامج التدخل الصحي المطور والمكيف (برنامج Be Your Best) حقق نتائج واعدة مع انخفاض بنسبة 60% في المشكلات السلوكية الكلية وزيادة بنسبة 100% في الرفاه العاطفي والاجتماعي الإجمالي بين المشاركين. وأكبر قدر من الزيادة في الرفاهية العاطفية والاجتماعية كان للمقياس الفردي بين الأشخاص ومقياس إدارة الإجهاد (100% لكل منهما). يتبع ذلك مقياس الشخصيات البينية ومقياس القدرة على التكيف ومقياس المزاج العام (93.33% لكل منهما) بينما كان أعلى قدر من الانخفاض هو النطاق الفرعي للقلق/الاكتئاب (73.33%) والسلوك العدواني (73.33%)، ثم تليها مشاكل الانتباه (66.67%) وتخفيض بنسبة 60% للمقاييس الفرعية المسحوبة/المكتتبة ومشكلات الفكر والمشكلات الأخرى. وكان أصغر انخفاض بين النطاقات الفرعية للشكاوى الجسدية والمشكلات الاجتماعية والسلوك المخالف للقواعد (53.33% لكل منهما). ويؤمل أن يمكن تكرار برنامج التدخل المطور وتنفيذه في منظمات مختلفة في جميع أنحاء البلاد للمساعدة في زيادة رفاهية المراهقين الآخرين المصابين بفيروس نقص المناعة البشرية / الإيدز.

الكلمات المفتاحية: فيروس نقص المناعة البشرية/ الإيدز، برنامج التدخل، البحث التشاركي، الرفاه.

APPROVAL PAGE

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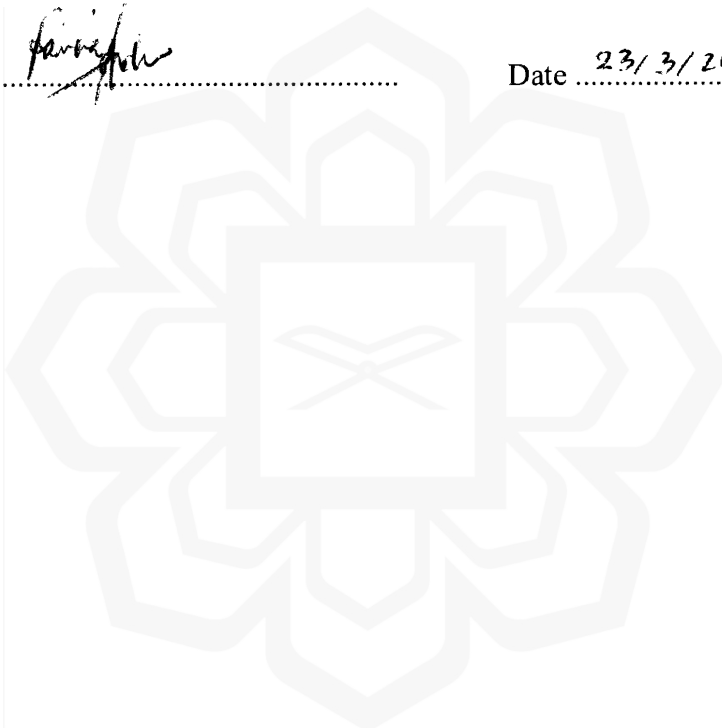
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DECLARATION

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.

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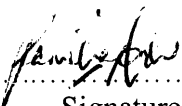
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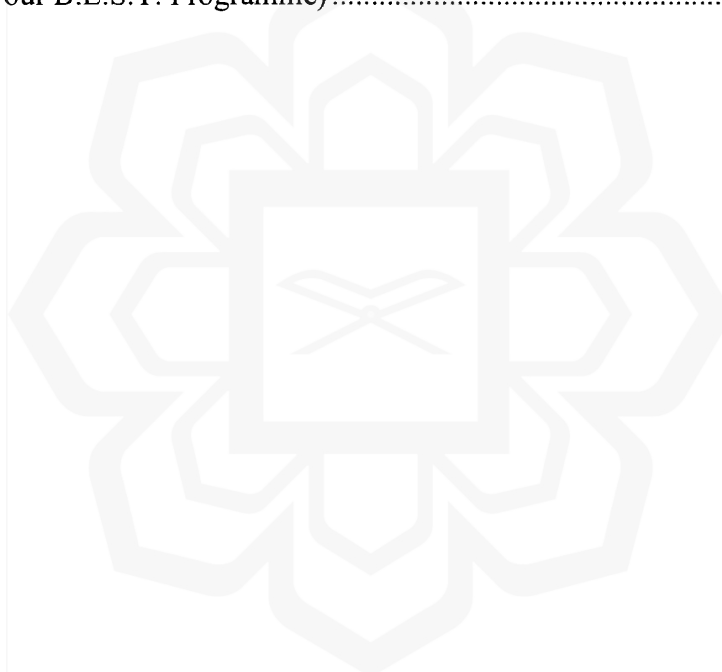
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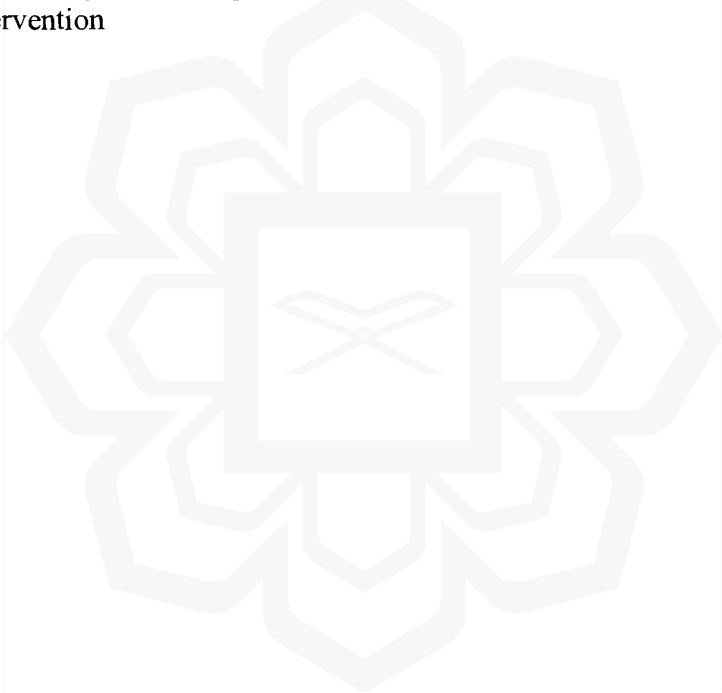
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CHAPTER ONE

INTRODUCTION

1.1 OVERVIEW OF THE CHAPTER

This chapter discusses the background of the present study, the overview of the background of the study and the statement of the problem. Furthermore, it also deliberates the research objective, research question, significance of the study and definition of terms.

1.2 BACKGROUND OF THE STUDY

Adolescence is described as the transition in human growth that happens after childhood and before adulthood ranging from the ages of 10 to 19 (World Health Organization (WHO), 2013). It is also a time of puberty whereby changes in psychological and physical growth occur (Ge, Conger, & Elder, 2001). Individuals in this stage of life comprise 20% of the world's population (WHO, 2013).

Generally, adolescents face various physical, cognitive and socio-emotional developmental changes at puberty (Santrock, 2014). Among some of the common causes of stressors in their lives, as highlighted in literature, include facing circumstances with adversity such as rapid changes and turmoil in social cliques, self-esteem, adversity (losses or death of a loved one), family background issues or even being diagnosed with a physical illness (Smetana, Campione-Barr, & Metzger, 2006). Although it has been said that adolescents face a myriad of developmental problems (Sacker, 2012), most adolescents develop smoothly into adulthood (Arnett, 2007). Some traverse smoothly through a normal adolescence period (Noor & Alwi, 2013) while some undergo stress due to various stressors (Galvan & Rahdar, 2013). There are