THE RELATIONSHIP BETWEEN ILLNESS REPRESENTATIONS, COPING AND QUALITY OF LIFE AMONG PATIENTS UNDERGOING HAEMODIALYSIS IN MALAYSIA'S NGO-BASED HAEMODIALYSIS CENTRES

BY

FATANAH BINTI RAMLEE

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Kulliyyah of Islamic Revealed Knowledge and Human
Sciences
International Islamic University
Malaysia

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ABSTRACT

The aim of the present cross-sectional study is to investigate the relationship between illness representations, coping and quality of life among patients undergoing haemodialysis in Malaysian NGO-based haemodialysis centres. The theoretical framework of the study was Leventhal's Common Sense Model of Self-regulation of Health and Illness (1984). The Illness representations, coping and quality of life were assessed by the Revised Illness Perception Questionnaire (IPQ-R), Brief COPE and Short Form 12-Item Health Survey Questionnaire v2 (SF-12v2) respectively. One hundred and four patients undergoing haemodialysis (79 males and 25 females) participated in the study based on purposive and convenience sampling. The analyses supported Hypothesis One but failed to support Hypothesis Two. The results indicate that perceived consequences ($r = -0.365$, $p < 0.01$), illness coherence ($r = 0.203$, $p < 0.01$) and emotional representation ($r = -0.317$, $p < 0.01$) were found to have significant relationship with quality of life. However, adaptive coping did not mediate perceived consequences and physical component summary (PCS) of quality of life in the present sample. The results suggest the importance of patients' representations of illness in their mental and physical health. Psychological assessment is proposed to be part of the patients' treatment protocol. Any development programmes in educating patients or care takers such as families, nurses, physicians and others would need to take into account patients' own representations of the end-stage renal disease (ESRD).

خلاصة البحث

تهدف هذه الدراسة العرضية المتزامنة إلى فحص علاقة التمثلات المرضية، والتأقلم مع المرض؛ مع نوعية الحياة وسط المرضى الذين يخضعون لغسيل الكلى في مراكز غسيل الكلى لدى المنظمات الماليزية غير الحكومية. والأساس النظري لهذه الدراسة هو نموذج التنظيم الذاتي للصحة والمرض، وفق الإحساس العام الذي وضعه ليفينثال عام 1984م. وتم تقييم التمثل المرضي والتأقلم مع المرض؛ مع نوعية الحياة عبر الاستبيان المنقح لتصور المرض، ومقياس التأقلم الموجز، و استمارة الاستبيان الصحي القصيرة ذات الاثني عشرة بنداً على التوالي. شارك في الدراسة 104 مريضاً يمثلون عيّنة هادفة مناسبة للذين يخضعون لغسيل الكلى، كان الذكور منهم 79، بينما الإناث مثلن 25 فرداً من العيّنة. وأيّد التحليل الفرضية الأولى ولم يؤيد الفرضية الثانية للبحث. وأشارتْ نتائج الدراسة أن الآثار المتوقعة ($r=-0.365, p<0.01$)، وتماسك المرض ($r=0.203, p<0.01$)، و التمثلات العاطفية ($r=-0.317, p<0.01$) لها علاقة إيجابية مع نوعية الحياة، إلا أنّ التأقلم أو التكيف على المرض لم يحقق المتوسط في الآثار المتوقعة، ولا مجمل المكونات البدنية لنوعية الحياة في عيّنة الدراسة الحالية. وأشارتْ الدراسة إلى أهمية التمثلات المرضية للمرضى في الصحة العقلية والبدنية. و من ثَمّ تم اقتراح التقييم النفسي ليكون جزءاً من جدول أعمال علاج المرضى، وأشارتْ الدراسة كذلك أن أيّ برامج تطويرية لتوعية المرضى، أو للقائمين على رعايتهم من أُسر، أو ممرضات، أو أطباء لا بد أن تراعي تمثلات مرضى الكلى، خاصة في نهاية مرحلة المرض.

APPROVAL PAGE

I certify that I have supervised and read this study and that in my opinion, it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a thesis for the degree of Master of Human Sciences (Psychology).

……………………………………
Hariyati Shahrima Abdul Majid
Supervisor

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a thesis for the degree of Master of Human Sciences (Psychology).

……………………………………
Meriam Omar Din
Examiner

This thesis was submitted to the Department of Psychology and is accepted as a fulfilment of the requirement for the degree of Master of Human Sciences (Psychology).

……………………………………
Harris Shah Abd Hamid
Head,
Department of Psychology

This thesis was submitted to the Kulliyyah of Islamic Revealed Knowledge and Human Sciences and is accepted as a fulfilment of the requirement for the degree of Master of Human Sciences (Psychology).

……………………………………
Mahmood Zuhdi Abd Majid
Dean,
Kulliyyah of Islamic Revealed
Knowledge and Human Sciences

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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I am dedicating this dissertation to my mother *Habibah Ismail* whose love I treasure most and in the fond memory of my late father *Ramlee Ismail*, whose wisdom and passion for knowledge has always inspired me.

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LIST OF ABBREVIATIONS

CAPD	Continuous ambulatory peritoneal dialysis
ESRD	End-stage renal disease
HD	Haemodialysis
IPQ-R	The Revised Illness Perception Questionnaire
PD	Peritoneal dialysis
QOL	Quality of life
SF-12v2	Short Form 12-Item Health Survey Questionnaire v2
SJAM	St John Ambulance Malaysia
WHO	World Health Organization

CHAPTER ONE

INTRODUCTION

> *Do they not look at the camels, how they are created? And at the heaven, how it is raised? And at the mountains, how they are rooted (and fixed firm)? And at the earth, how it is outspread? So remind them (O Muhammad peace be upon him) – you are only one who reminds* (Al-Ghashiyah: 17-21).

This chapter discusses the background of this study, statement of the problem, significance of the study, research objectives and conceptual and operational definitions of the variables.

1.1 BACKGROUND OF STUDY

Chronic illnesses have become a major cause of disability and mortality for many individuals in Malaysia. Individuals diagnosed with chronic illnesses such as cancer, cardiovascular disease and end-stage renal disease (ESRD) will need to live for years with their medical condition. Once diagnosed, they may need to depend on pharmacological treatment for the rest of their lives (de Ridder, Greenen, Kuijer & van Middendorp, 2008). In Malaysia, patients with ESRD undergoing dialysis, for instance, have increased from 88 per million population in 2001 to 170 per million population in 2009 (Lim, Ong, & Goh, 2011). The statistics is grim as the number continues to increase steadily over the years and approximately 12% of patients die annually.

ESRD is a condition that occurs when the function of the kidneys decreases to less than 10% of normal and it is unable to perform life-sustaining removal of waste and water from the body as it normally does (Kamaroff, 1999). Diabetes, glomerulonephritis, chronic hypertension and familial polycystic renal disease are among the factors that commonly cause ESRD (Petrie, 2007). ESRD is fatal if patients do not receive proper treatment or therapy. Patients with ESRD need renal replacement therapy that is necessary for survival. Current treatments available for patients living with ESRD include peritoneal dialysis (PD), haemodialysis (HD) and kidney transplantation (Christensen & Ehlers, 2002; Kamaroff, 1999). Haemodialysis, a preferred treatment, works by cleansing a patient's blood through artificial kidney machines three times a week for about four hours each session at dialysis centres (Petrie, 2007) or at home for some patients (Kamaroff, 1999). It means that the artificial kidneys only work 12 hours per week in contrast to the kidneys of healthy people which work 24 hours every day. In Malaysia, 98% of patients undergoing haemodialysis are on three dialysis sessions per week (Lim, Ong & Goh, 2011). According to Lim, Ong and Goh (2011) in the 18th Report of the Malaysian Dialysis & Transplant Registry 2010, there are 618 dialysis centres to cater for the patients with ESRD in Malaysia.

Socrates said that "*You should put the highest value, not on living, but on living well*" (Ring, 2007). But, this saying might not reflect the lives of patients with ESRD specifically patients undergoing haemodialysis. Despite advancements in available treatments for patients living with ESRD, this condition continues to negatively impact the illness outcomes, particularly on the patients' quality of life. Patients experience multiple potential losses of functions and need to make significant and often times, difficult lifestyle changes such as managing strict dietary intake, performing regular physical activities as well as managing pain (Fowler & Baas, 2006; Petrie & Reynolds, 2007). The diagnosis of ESRD itself is highly distressing. Patients have to cope with the possibility that their body functions have changed and may remain permanently impaired (Petrie & Reynolds, 2007). In other words, patients will not only experience decreases in physiological function but also continuous psychological adjustment such as loss of self-concept and self-esteem, feelings of uncertainty about the future and feelings of guilt towards family members (Christensen & Ehlers, 2002; Cinar, Barlaz & Alpa, 2009; Timmers, Thong, Dekker, Boeschoten, Heijmans, Rijken, et al., 2008). Patients may also have to bear the burden of financial losses (Cinar, Barlaz, & Alpa, 2009). On top of the medical and psychological outcomes, patients with ESRD face multiple demands and restrictions travelling to dialysis centres and adhering to strict medical regimens while on dialysis (Wolf & Mori, 2009). These changes understandably impact the patients' quality of life. Niu and Li (2005) found that patients with ESRD obtained the lowest scores for psychological health domain in comparison to other domains namely physical health, social relationships and environment of the World Health Organization Questionnaire on Quality of Life: BREF – Taiwan Version. Hence, it is not surprising that the quality of life among patients living with ESRD is lower compared to the general public (Cleary & Drennan, 2005) as they have to cope with the burden of the illness, the changes, the challenges and the routines that they have never experienced before.

Some studies have suggested that haemodialysis, although the preferred treatment, may have more negative impacts on patients with ESRD, especially on their quality of life compared to other treatment options. For instance, Griva, Jayasena, Devenport, Harrison and Newman (2009) found that kidney transplant patients have better quality of life than patients undergoing dialysis. Their finding is consistent with a study conducted by Niu and Li (2005) which reported that the quality of life in patients with ESRD is poorer among patients undergoing dialysis compared to patients who received kidney transplant. Patients who received kidney transplants are also more likely to have job security; better financial support, better social support and better social network connections. A meta-analysis study on quality of life revealed that patients who received kidney transplant scored significantly higher than patients on dialysis (including HD and PD) in all dimensions of the Medical Outcomes Study Short Form 36-Item health Survey (SF-36) except for mental health dimension that did not show any significant difference between kidney transplant recipients and patients undergoing PD (Liem, Bosch, Arends, Heijenbrok-Kal & Hunink, 2007). Lok (1996) found that patients undergoing haemodialysis perceived having a poorer quality of life than patients undergoing continuous ambulatory peritoneal dialysis (CAPD). These studies suggest that patients undergoing haemodialysis may experience more adverse effects in terms of quality of life compared to those who undergo other types of ESRD treatments.

In addition to the types of treatment, various factors contributing to the quality of life in patients with ESRD have been studied. Among the factors are clinical variables, medical technology, socio-demographic and psychosocial factors (Mucsi, 2008). A psychological factor that has been found to be significant in quality of life studies is illness representations (i.e. Fowler & Baas, 2006; Timmers et al., 2008). According to Petrie, Jago and Devcich (2007), illness representations correlate significantly with numerous outcomes such as self-management behaviours and quality of life. Patients develop their own model of belief or perception about the illness based on their experience of the illness (Weinman & Petrie, 1997). Referring to Leventhal, Benyamini and Shafer (2007), the information that forms the patients' perception may come from different sources such as what other people around them say, patients' understanding and misunderstanding of what the doctors inform them, their observations of other people and the experience with their own physical and emotional condition.

Moreover, illness representations as perceived by the patients differ from the medical staff's or even the care takers' perception, as well as other patients' perceptions, whether they are experiencing the same or different medical conditions (Petrie, Jago & Devcich, 2007). However, in general, their perceptions revolve around several themes which are identity, cause, timeline, consequences, control/ cure and emotional representation (Hagger & Orbell, 2003; Petrie, Jago & Devcich, 2007; Weinman, Petrie, Moss-Morris & Horne, 1996). First, *identity* refers to the patients' belief about the labels or symptoms of the illness such as itchy skin, headache and nausea. Second, *cause* refers to the patients' belief about the factors that cause the illness such as hereditary, eating habits, stress and others. Third, the *timeline* refers to the patients' perception on the course and recurrence of the illness such as their belief that the illness is continuous for the rest of their life. Fourth, the *consequences* theme is when patients perceive the effect of the illness on their life such as the seriousness of the illness. Fifth, the *control/ cure* theme refers to the perception of controllability or curability of the illness. Finally, *emotional representation* is the patients' responses to the illness such as sadness, fear and others.

A study has found that, for instance, lower quality of life is associated significantly with more serious perceived consequences among patients undergoing haemodialysis (Timmers et al., 2008). In other words, patients who perceive that the consequence of living with ESRD is adverse are more likely to experience higher emotional distress and poorer physical and social functioning. This condition may affect the patients' adjustment to cope with the illness. Patients need to cope with their condition beginning from the earliest stage of diagnosis, dealing with the symptoms and experiencing the stressful life changes (Petrie & Reynolds, 2007) such as being connected to the haemodialysis machine every alternate days (Kaptein, van Dejk, Broadbent, Falzon, Thong & Dekker, 2010). As mentioned by Hale, Treharne and Kitas (2007), the biggest challenge of the illness is the effect it has on the patients' ability to continue living a "normal" daily life. Hence, coping with the illness is another important variable that could influence the patient's quality of life.

Typically coping can be classified into either problem-focused coping or emotion-focused coping (Awasthi & Mishra, 2011). Problem-focused coping is a proactive strategy whereby one alters the stressful situation by doing something to adjust the stressor, while emotion-focused coping is a passive and avoidance strategy in managing the stressful emotions (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986). Both problem-focused and emotion-focused coping can be adaptive or maladaptive in certain situation (Petrie & Reynolds, 2007) because the patients' coping can change from one time to another depending on the stressful encounter (Lazarus, 1993). For example, positive reframing, acceptance and social support seeking are adaptive coping regardless of the types of chronic illness experienced by the patients (Petrie & Reynolds, 2007). Lazarus (1993) believed that "adaptive is the effectiveness of coping in improving the adaptational outcome, for example, morale, physical health and social functioning" (p. 237). Such coping strategies are influenced by the patients' own understanding of illness. According to Hagger and Orbell (2003), coping mediates the relationship between illness representations and quality of life. In other words, the patients' quality of life can be influenced by the way the patients perceive their illness as well as the way they handle the adverse effects of living with the illness. Fowler and Baas (2006) proposed in their concluding paragraph to include coping elements in future study. Therefore, the present study is an attempt to investigate the relationship between illness representations, coping strategies and quality of life in patients with ESRD undergoing haemodialysis in Malaysia.

1.2 STATEMENT OF PROBLEM

With technological advances in treatment and management of chronic illnesses, patients living with ESRD and undergoing haemodialysis are expected to perform normal daily functioning (i.e. Kamaroff, 1999; Niu & Li, 2005). Patients are expected to adhere to treatment regime, modify their health-related lifestyles and perform social and occupational functions more smoothly and easily. However, research shows that, despite the advancements made in providing better health care facilities, patients continue to experience deteriorated quality of life (i.e. Niu & Li, 2005; Timmers et al., 2008). This leads to the question of psychological implications of ESRD especially on patients undergoing haemodialysis. Therefore, understanding the ways by which patients represent their illness may help health care providers to offer patients services that improve the way they cope with living with ESRD. Through this understanding, health care providers may help patients live with a better quality of life. The present study, hence, aims to examine the role illness representations play in influencing health and psychological outcomes of patients living with ESRD undergoing haemodialysis. It also aims to clarify the role coping plays in the relationship between illness representations and quality of life.

1.3 SIGNIFICANCE OF STUDY

The literature suggests that not much is known of the relationship between illness representations, coping and quality of life in patients with ESRD especially in Malaysia. It is not surprising because there are not many publications in the context of psychological research on ESRD in comparison to psychological research on other medical conditions. According to Kaptein, van Dejk, Broadbent, Falzon, Thong and Dekker (2010), the literature search in PubMed (29 August 2009) on "end-stage renal disease and psychology" revealed 2562 hits compared to 35204 hits for "cancer and psychology" and 28280 hits for "cardiovascular disorders and psychology". Meanwhile, Chilcot (2010) used "illness representations and ESRD" and "illness perceptions" was added in later search via PubMed, Psycinfo and the Web of Knowledge databases. The search revealed eight studies that examined illness representations in end-stage renal disease.

Hence, firstly the present study will fill the gap in the existing literature on the modifiable roles of illness representations and coping in influencing the quality of life among patients with ESRD particularly among Malaysian patients who are undergoing haemodialysis. Secondly, it is also hoped that based on the findings of this study, recommendations can be proposed to help health care professionals, care takers, counsellors and psychologists to design health promotion and intervention programs appropriate for Malaysians as they have an understanding on patients' representations of illness, coping and quality of life.

1.4 RESEARCH OBJECTIVES

The objectives of this research are:

1. To investigate on how illness representation constructs relate to quality of life among Malaysian patients with ESRD undergoing haemodialysis.
2. To examine the mediating effect of coping in the relationship between illness representation constructs and quality of life among Malaysian patients with ESRD undergoing haemodialysis.

1.5 CONCEPTUAL AND OPERATIONAL DEFINITIONS

Illness representations

Illness representation is synonymous to illness beliefs, illness perceptions, and illness cognition or illness schemata. Illness representation is conceptually defined as patient's common-sense definition of health threats and the patient's perception and understanding of the disease and treatment (Kaptein & Broadbent, 2007). Weinman and Petrie (1997) suggested that patients develop cognitive models of the bodily changes that reflect transient symptoms or more long-term illness just like normal people construct representations of the external world to explain and predict events. Illness representations is operationally defined by the scores of each six subscales of the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002) which are timelines (timeline acute/ chronic and timeline cyclical), consequences, controllability (personal control and treatment control) and emotional representations.

Coping

Coping refers to the cognitive, behavioural and emotional means that individuals manage their stressful situations (Petrie & Reynolds, 2007). Petrie and Reynolds (2007) mentioned that Lazarus and Folkman's transactional model (1984) views patients' coping responses as determined by their evaluation of the degree of threat posed by an illness and the resources seen as being available to help them cope in the situation. In the present study, coping is operationally defined by scores of the two constructs derived from the Brief COPE Scales (Carver, 1997), adaptive coping and maladaptive coping.

Quality of life

Quality of life is conceptualized as a multidimensional concept which includes physical, psychological and social functioning and well-being (Spilker, 1990 as cited in Cleary & Drennan, 2005). In the present study, quality of life is operationally defined via the Physical Component Summary (PCS-12) scores and Mental Component Summary (MCS-12) score of Short Form 12-items Health Survey Questionnaire Version 2 (Ware, Kosinski, Turner-Bowker, Sundaram, Gandek & Maruish, 2009).