

THE STAGES OF DENIAL AND ACCEPTANCE AMONG PATIENTS WITH CHRONIC KIDNEY DISEASE

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Abstract

Around 400 new cases of chronic kidney disease are being delivered to nephrology clinics every year at an average of 20 patients a day. The current study aimed to construct a test instrument to assess the stages of acceptance and denial among patients with chronic kidney disease to identify the degree of denial among patients as a basis for intervention. A total of 116 participants took part in the study, consisting of new and follow-up cases. Six factors emerged from the study which characterised the aspects of denial and acceptance. The Renal Care Readiness Scale has been identified to have a good internal consistency.

Key words: acceptance, denial, kidney disease

Introduction

Nephrologists and chronic illness educators at a nephrology clinic caters to at least 20 patients each day, and statistics shows that they enrol at least 438 patients of more each year and continues to serve more patients diagnosed with chronic kidney disease (CKD). These cases comprise new referrals and regular patient follow-up wherein diagnosis of CKD has been identified. All these patients undergo complete diagnostics for physicians to determine CKD.

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True to the cause of educating each patient about the nature of their disease, health counsellors continue further interviews and educate each patient about their condition, prognosis, signs, symptoms, complications, and how to cope with their situation in preparation for treatment. However, there were still patients who seem to be in a state of denial about their illness; either they do not understand what is really happening with them or remain in denial despite being advised of the consequence of their disease and refuse to plan and prepare for it financially and psychologically. During the interview process health counsellors and nurses have observed a significant number of patients who are in a state of denial about some aspects of their disease and manifest in several ways. Some patients refuse to seek further treatment and lifestyle changes because they claim that they do not feel any symptom at all and that they feel “fine” and “healthy” to the point that others would stop seeing their doctors and discontinue their CKD follow-up. Most of the patients were not seen by anyone and would refuse to seek treatment. As they were followed-up through phone calls, some would still seek for a second opinion about their illness, even though they were already showing signs and symptoms related to a patient having CKD. Others refused to hear that they are already in need of palliative care such as undergoing regular dialysis or kidney transplantation, even the consequences of undergoing no treatment has been explained thoroughly by their physicians and health counsellors. These are just some of a very long list of instances where patients expressed denial of their illness and failed to realise the degree of seriousness of their situation.

Denial as a defence mechanism entails refusing to believe a reality or fact of life. A fitting example would be when a patient suffering from substance abuse refuses to acknowledge the fact that taking drugs is harmful. On the other hand, acceptance is exhibited when a patient is fully aware of his condition and has come to terms with his illness. It is also when a patient can be completely adaptive to his environment and other aspects of his life. In many studies, denial may be maladaptive at a certain time depending on how much it will be prolonged.

In a study which investigated the level of acceptance among Turkish patients who suffer from chronic pain, it has been revealed that patients who have high acceptance experienced less depression and stress compared with those who have low acceptance level (Besen & Esen, 2012). It is of great significance for healthcare providers to recognise and appraise the patient’s degree of denial and acceptance so that it can be addressed during the treatment process. Health practitioners need to keep in mind that not all patients who manifest scenarios similar to those mentioned above are implicitly in a state of denial.

A host of factors come into play in any given moment during the encounter with the patient: patients may not fully understand the nature of their disease and the treatment process when the attending physician explains it, which could suggest that further education is required instead of denial. Moreover, the persistence of a patient that there may still be hope left despite being diagnosed with CKD may be acting on a personal belief system or when the patient simply does not have the means or resources to further continue the treatment can be a reason why they no longer show up during their follow-ups.

Aims

It is clear that there is a need for an assessment tool that healthcare practitioners can use to identify the degree of acceptance and denial among patients in order to know their readiness before administering the CKD course modules. The result of this study will help the CKD educators to identify patients who are either in acceptance or denial. An intervention programme or added module dealing with aspects of denial and acceptance might be included in the course curriculum of the patients. Patients in the denial stage might benefit from pre-modular education or pre-orientation about the CKD programme and those on the acceptance stage will follow the regular inflow of CKD modules.

The main objective of this study is to construct a reliable and valid test instrument in assessing the stage of acceptance and denial among patients with CKD. In addition, the researchers also aim to provide data to physicians so that the patient's psychosocial needs may be addressed by establishing counselling programmes specifically designed for the patient going through stages of denial.

Review of Related Studies

Acceptance and denial are two independent and fluctuating coping mechanisms which operate on all patients and it appears to form an important aspect of the coping process. Healthcare professionals commonly refer to the terms acceptance and denial when describing a patient's response to chronic illness.

Denial is commonly encountered in clinical practice especially at those who are dealing with serious illness. It is an important and complex psychological concept. It was first used in psychoanalytical theory where Anna Freud described denial as a defence mechanism. When taken

as a defence mechanism, it entails refusing to believe a reality or fact of life, which has the goal of reducing the unpleasant effects of discovering the reality. Denial was also viewed as pathological for many years. It has been argued that denial is composed of a number of related components. It has many aspects and it may have different meanings, depending on one's theoretical stance.

In a pioneering study, Jacobsen & Lowery (1992) defined five dimensions of denial: denial of illness; denial of impact on the future; unrealistic expectations from care; denial for need of care; and, denial of feelings related to illness. On the other hand, acceptance and adaptive state is achieved when a person experiences peace and acceptance to the inevitable and is concerned with pursuing worthwhile life goals. There are five dimensions described in this study: coping, adjustment, avoidance, compensation, perceived benefits, and psychological distress.

A corpus of studies recognises the importance of acceptance and denial across different diseases as an important goal in managing chronic illnesses. A study among chronic pain patients (Esteve, Maestre, & Martinez, 2007) found out that patients suffer less from emotional distress when proper coping strategies were used. This is further supported by another study on chronic pain sufferers (Costa & Pinto-Gouveia, 2011), where acceptance of pain helps patients pursue life activities in a normal manner even when pain is being experienced. A shift from controlling the pain, wrestling with it, has changed into acknowledging the pain, giving up unproductive attempts to control it and acting as if pain is not necessarily a disability. The patient's efforts are committed to living a satisfying life despite pain. It was found out that those patients with high level of acceptance presented less depression and stress compared with those who have low level of acceptance. Of course, this has to be coupled with medical intervention. For instance, it was observed that patients choosing conservative kidney management (CKM) maintained quality of life. Adjusted median survival from recruitment was 13 months shorter for CKM patients than hemodialysis patients (Da Silva-Gane et al., 2012).

In CKD stage, 5 patients over 75 years, who received early specialist nephrology care and who follow a planned management pathway, had their chances of survival through dialysis substantially reduced by comorbidity and ischaemic heart disease in particular. Comorbidity should be a major consideration when advising elderly patients for or against dialysis (Murtagh et al., 2007).

In addition, another group of researchers tried to establish the relationship between patterns of coping and distress among breast cancer patients during a pre-surgery and post-surgery after three months (Roussi, Krikeli, Hatzidimitriour, & Koutri, 2007). They found out that those patients

who used emotion-focused engagement coping at pre-surgery experienced less distress three months later compared to those who have not used any coping strategy. Recently, the relationship between coping and resilience among diabetic patients (Jaser & White, 2010) was also studied. They found out that coping strategies such as problem solving, emotional expression, acceptance and distraction were related to higher social competence, better quality of life and better metabolic control. Similar observations have also been revealed among people who are trying to improve levels of body satisfaction and positive affect (Relajo, 2015).

Finally, culture is recognised as a determinant to the types of coping strategies used by an individual. One study (Chy, Concepcion, Conferido, & Coretico, 2009) has highlighted three main themes: will power, acceptance and positive thinking. Coping was also recognised as an important tool so that patients can keep up with certain stressful events, making their lives more tolerable.

On the other hand, a study recognised the adaptive and maladaptive effect of denial among cancer patients (Vos & de Haes, 2007). Results showed that the effect seemed to depend on the concept of denial used. Distractive strategies seemed to have helped patients reduce stress while passive escape turned out to decrease psychological well-being. Another study conducted among patients with lung cancer (Vos, Putter, van Houwelingen & de Haes, 2010) came up with interesting findings. First, patients are expected to display some degree of denial since patients are subjected to an overwhelming and very stressful reality that they are afflicted with such a disease. Second, patients showed an increasing degree of denial a few months after being diagnosed which should also be expected since patients could realise that the prospect of death is near. This means that doctors and health educators need to address and manage issues of mortality to their patients as the course of the illness progresses. In addition, a study among patients with diabetic kidney (Williams, Manias & Walker, 2009) focused on the irrational thinking of patients and how it affects medical, heuristic adherence and denial.

In the current study, however, denial was used by patients to enhance coping necessary to manage complex health conditions which is a testament that health educators need to be certain if the patient's denial is adaptive or maladaptive so it can be addressed properly during the course of the treatment.

Different measures and scales have been developed in the past which either measure denial or acceptance of various chronic illnesses. A good example would be the 18-item Illness Cognition Questionnaire (International Society of Behavioural Medicine, 2009) which focuses on helplessness, acceptance and perceived benefits. Another one is the Multidimensional Acceptance

of Loss or MALS (Ferrin, Chan, Chronister, Chiu, 2010), a 60-item test which is used to measure four value changes in Beatrice-Wright's acceptance theory, namely: enlarging the scope of values, containing the effects of the disability, subordinating the physique and transforming comparative status values to asset values.

The theoretical background of MALS emphasises the fact that with acceptance and disability an individual can reach new life values, meanings and goals and reach a new positive self-concept. In an attempt to view disability from the perspective of adaptation and acceptance of one's life instead of grief and loss, a group of researchers came up with the Acceptance of Chronic Health Conditions Scale (Stuifbergen, Becker, Blazis, & Beal, 2008), a 10-item questionnaire based on the original Acceptance of Illness Scale. And finally, the Levine Denial of Illness Scale, a 24-item test which has a total of five subscales deals with denial experienced by patients.

As observed by the researchers, most of the previous tests measured only one aspect which might not be sufficient enough to properly measure how patients respond to illness. In this study, both denial and acceptance experienced by patients are measured to come up with a more efficient way of telling which patient will require more intervention and counselling as well as predict future medical adherence which is very important in managing CKD. Its length is just about right so as not to overwhelm the patients. And lastly, questions on the Renal Care Readiness Scale (RCRS) can also be used for other types of illness which would allow comparison across other groups.

Method

Participants

The participants (N = 116) comprise of all new incoming and follow-up cases at a nephrology clinic. There were 55 males (47.4%) and 61 females (52.6%). The age of the participants ranges from 19-72 ($M = 46.41$, $SD = 16.12$). Among these patients, 56 were new cases (48.3%); 57 were follow-ups (49.1%) and 3 opted not to give this information (2.6%). The stage of their CKD varies from stages 1 to 5.

Procedure

The study was conducted in a hospital where diagnoses of kidney diseases and problems were done. CKD patients were sent to their respective counselors for debriefing.

The researchers came up with the original 86 highly-observable behaviour manifested by most patients with chronic illness. A panel for validating the test items comprising five nephrologists, a guidance counsellor and a psychologist. After communicating with the director of the clinic, researchers began the trial run. Some items were eliminated and revised after this trial run and items were reduced to 68. The first trial was conducted to 25 patients.

Most patients complained with numerous items and they left those items unanswered. Since most of the items were left unanswered, the researchers reduced the number of items again by keeping only those items that the panel considered to be correct (i.e. 5/5 face validity rating), namely 20 test items. The data was encoded and demographic information was included.

Data Analysis

The researchers utilized SPSS version 20 to analyse the data gathered from the patients of a nephrology clinic. Mean, standard deviation and frequency table were used to analyse the demographic profile of the participants. In addition, the researchers also utilized factor analysis using varimax rotation with Kaiser normalisation to come up with the six-factor loading which have eigenvalues greater than 1.0. Cronbach's alpha was also used to measure internal consistency of the data.

Results

The 20-item questionnaire was factor analysed using the principal component and varimax with Kaiser normalisation to delineate the underlying factors of RCRS. The Kaiser-Meyer-Olkin (KMO) measure yields .69 which suggests that there is sufficient sampling for factor analysis to proceed. Table 1 shows these results. Table 2 enumerates the items of the scale.

Table 1. *Summary of the Factors for Renal Readiness Scale*

FACTORS	EIGENVALUE	VARIANCE (%)	α
Appreciation	4.49	17.37	.84
Adherence	2.91	11.11	.73
Assumption	1.96	10.55	.64
Awareness	1.61	9.66	.68
Anticipation	1.21	9.37	.61
Affective	1.14	8.65	.64

Table 2. *Items for Renal Care Readiness Scale*

ITEMS	FACTOR LOADING
I can still have a good lifestyle despite my illness.	.49
My life is still worth living although I have this condition.	.59
I should avoid situations that might make my condition worse.	.74
I should avoid my bad habits.	.73
Having this condition somehow made me appreciate life even more.	.87
Facing all the challenges my illness brought about has made me a better person.	.79
There is no need to follow-up on my condition once I started feeling better.	.76
I will only seek treatment once I start to feel the signs and symptoms.	.84
I do not need to undergo any treatment.	.73
I am physically healthy.	.73
My symptoms usually fade away; I do not need to worry.	.78
There is no need to prepare for whatever it is that lies ahead.	.65
I am not afraid of my disease.	.53
I feel depressed after the doctor told me about my condition.	.68
My family and I should learn about my disease.	.67
I have to change my lifestyle to cope with my condition.	.74
I believe that I will be completely cured one day with regular treatment.	.79
My doctor told me that my disease will be completely cured.	.69
I feel depressed when I think about the challenges that I will go through.	.83
I fear and worry about my condition.	.80

The researchers came up with six factors: (1) appreciation; (2) adherence; (3) assumption; (4) awareness; (5) anticipation; and, (5) affective.

Appreciation refers to the patient's new and enlightened perspective of life after accepting the fact that they have chronic illness. Patients manifest a renewed appreciation of their lives, a newly found significance and value of their existence. Since the patient has come to terms with his/her illness, to some degree, they are able to utilize better coping strategies in the face of difficulties of being chronically ill.

Adherence refers to the patients' willingness to subject themselves to treatment and their commitment in participating in their own healthcare. Patients who are in denial often display a degree of stubbornness toward treatment which manifests itself in different ways e.g. missing follow-ups, not taking prescribed medications and outright disbelief.

Assumption is characterised as the erroneous expectation of patients that is rooted in the belief that they are not seriously ill; this is a marked behaviour manifested by patients who are denying or belittling the effects of their illness.

Awareness is the patient's overall reaction upon being informed about their illness. Patients who are in denial will fail to acknowledge the right emotional response upon being diagnosed i.e. sadness, loneliness, depression and apathy. On the other hand, patients who have accepted it will most probably utilise solution-focused problem solving in the attempt to manage illness by learning more about it, thus making necessary changes to their lifestyle and displaying the right emotional response.

Anticipation is observed when a patient's reaction to their illness can range from right optimism to unreal hope or wishful thinking. Patients who exhibit high score on this scale may be showing extreme denial of their illness.

Affective refers to the accompanying psychological distress upon being diagnosed with chronic illness. Patients who display depression and a degree of anxiety over their illness are said to be more accepting of their illness. Those who do not show the right emotional response may be manifesting signs of denial.

Discussion

The distribution of the respondents according to their demographic profile is almost equal suggesting good external validity. The KMO of .69 also suggested that there is enough sample for factor analysis to proceed and its results are likely to be reliable. The data reduction came up with final six factor loadings whose eigenvalue is 1.0 and above. Moreover, the researchers decided that only items that have a value of .40 or greater will be retained to ensure good internal validity. The overall consistency is .71 which suggests acceptable internal consistency. In addition, each of the sub-dimensions were also subjected to Cronbach's alpha which came up with values ranging from .61 to .84, which also suggest that the RCRS has a high degree of reliability.

Conclusion

The RCRS has shown to have high reliability and good internal consistency. In addition, it also provides a new perspective taking into account both behavioural manifestations of denial and acceptance among chronically ill patients.

This research will provide health professionals and educators with the capability of assessing each patient's unique needs and tailor the counselling and intervention programme accordingly. For instance, in one study (Relajo, 2012), it has been observed that those with a high level of

Adversity Quotient (AQ) and moderate level of Spirituality Quotient (SQ) are better at dealing with their personal difficulties. Moreover, it can also be used as a tool to gauge the level of denial and acceptance of patients while undergoing the treatment process itself. These data can be a valuable tool to improve the patient's overall condition by managing adherence to treatment and help them learn better coping strategies as their illness progresses.

Limitations and Future Directions

There is a need for a psychological assessment tool for medically-ill patients to address the psychosocial problems and need to their nephrologists and be able to refer them to the other necessary healthcare professionals to help them ease their illness – both physically and psychologically. An early psychosocial intervention programme for this population will be effective in supporting their mental health, and in understanding more about the aspects of the illness to delay its progress. Further research may be needed to address the specific psychological need of each chronic kidney disease patient and fill the gap between the aspects of biomedical and behavioural intervention.

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