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PUBLIC HEALTH | RESEARCH ARTICLE

Living with diabetes: An exploratory study of illness representation and medication adherence in Ghana

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Abstract: *Background:* Compared to other chronic conditions, non-adherence to medication in diabetes patients is very high. This study explores the relationship between illness representation and medication adherence in diabetes patients in Ghana. *Method:* A total of 196 type 2 diabetes patients purposively and conveniently sampled from a tertiary hospital in Ghana responded to the Revised Illness Perception Questionnaire (IPQ-R) and the Medication Adherence Report Scale (MARS-5). The Pearson Moment Product correlation and the hierarchical multiple regression statistical tools were used to analyse the data. *Results:* Illness consequence and emotional representation were negatively related to medication adherence, while personal control positively accounted for significant variance in medication adherence. However, none of the selected key demographic variables (i.e. age, illness duration, gender, religion and education) independently accounted for any significant variance in medication adherence. *Conclusion:* Diabetes has a telling consequence on patients' life; the patient can do something to control diabetes; and the negative emotional representations concerning the disease have a significant influence on the degree of medication adherence by the patients. This observation has implications for the management and treatment plan of diabetes.

ABOUT THE AUTHORS

We have come to appreciate that health is a function of context, which is not just about the relevant background of health, but a dynamic element that sets the tone for the course of health in general. We are interested in psychological factors which affect the course and management of chronic diseases in under-served, low and middle income communities where chronic diseases are trivialized and less prioritized. There are also various commonly held negative perceptions about chronic illnesses which hinder the successful management and prevention of chronic illnesses. We believe research (like the present one) is the first step to understanding and undoing these negative perceptions and attitudes held by patients of chronic illnesses.

PUBLIC INTEREST STATEMENT

People with chronic conditions that present with (seemingly) no or less symptoms are often found not to adhere to their prescribed medication for disease control. Past research has indicated that the beliefs and expectations that people hold do translate into the actions that they take. The purpose of this study was to explore if the beliefs and expectations that diabetes patients hold concerning the disease influence their medication adherence behaviour. Data on patients' beliefs and expectations and medication adherence were gathered from 196 diabetes patients using self-report structured questionnaire. The results of the analysis showed that patients' beliefs about the control they have over the disease, their expected consequences of the disease, and the emotional responses they have in relation to the disease were independently related to their medication adherence behaviour. This result has implications for the management and treatment plan for the disease.

Subjects: Psychological Science; Health Psychology; Multidisciplinary Psychology; Social Psychology; Psychology and Nursing; Counseling Psychology; Mental Health; Health & Society; Public Health Policy and Practice; Medicine

Keywords: diabetes; Ghana; illness representation; medication adherence; illness beliefs; patient management; hyperglycemia

1. Introduction

Diabetes mellitus is one of the most common chronic diseases in most countries with a continuous increase in numbers in terms of incidence and prevalence. According to International Diabetes Federation (IDF) 2015 report, 1 in 11 adults have diabetes (415 million) worldwide. Again there were 266,200 cases of diabetes recorded in Ghana in 2015 with a prevalence rate of 1.9% in adults aged 20–79 years (IDF, 2015). Currently, majority of the people living with diabetes are found to be living in low- and middle-income countries and are expected to experience the greatest increase in cases of diabetes over the next 22 years (Guariguata et al., 2014). In terms of age and regional distribution of the disease burden of diabetes, persons within the 40–59 years bracket are the most affected with the highest proportion (61%) of the burden recorded in the Africa region and 67% in low-income countries (Guariguata et al., 2014). It is indicative from the statistics that diabetes poses a serious health threat to developing countries as the region bears the greater proportion of the disease burden.

Usually symptoms of diabetes are not severe, or may be absent (American Diabetes Association, 2010). Hence, hyperglycemia (abnormal high blood sugar level) may be present for a long time causing pathological and functional changes before a diagnosis is made or mismanagement after diagnosis (Arkkila & Gautier, 2003). The effects of hyperglycemia have been documented as regard long-term damage and failure of various organs including potential blindness (WHO, 2014), renal failure (Suissa, Hutchinson, Brophy, & Kezouh, 2006). However, long-term glycemic (blood sugar level) control has also been established as being fundamental to the management of diabetes and has been shown to reduce both microvascular and macrovascular complications (Asche, LaFleur, & Conner, 2011).

Healthy lifestyle choices including diet, exercise and weight control provide the foundation for managing diabetes but some patients in addition may need medication to achieve targeted blood sugar levels (Nathan et al., 2009). Nevertheless, despite adequate diagnosis and medical care, most patients often fail to derive the optimal clinical benefit of drug therapy because of medication non-adherence posing a pervasive clinical challenge (Rozenfeld, Hunt, Plauschinat, & Wong, 2008; Simoni, Frick, & Huang, 2006; Yu, Yu, & Nichol, 2010). However, among diabetes patients non-adherence is reported to be very high compared with other chronic conditions (Cramer, 2004; DiMatteo, 2004; Jambedu, 2006; Mann, Ponieman, Leventhal, & Halm, 2009).

In Ghana, adherence to anti-diabetic medication by patients is estimated to be low with the reported rate ranging between 40 and 50% (Jambedu, 2006). The implication is that, owing to the non-adherence, many diabetes patients are at higher risk of both acute and chronic complications. These complications may lead to higher need for hospitalization, additional health cost as well as increased levels of morbidity (Deshpande, Harris-Hayes, & Schootman, 2008). Research exploring illness practices among diabetes patients in Ghana identifies that diabetes patients rated biomedical management as the ideal and preferred practice. However they were constrained due to the psychosocial impact of the disease (specifically, daily drug and dietary management routines) and the high cost involved. As such there was a drive among diabetes patients for other practices such as cure seeking and medical inaction (Aikins, 2005). Again, it has been found in a study from Ghana that health is conceptualized as strength and so when their wellbeing and ability to engage in everyday practices are altered due to some form of medication they are taking, they are unlikely to continue taking the medication even though it helps in managing a diagnosed condition (Read, 2012).

In explaining health behaviors, psychosocial determinants are increasingly identified as impacting health and treatment (Sallis, Owen, & Fisher, 2008). A number of reasons has been given to the variations in patients' beliefs and treatment adherence among patients (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000; Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). The patients' beliefs based theory by Leventhal, Meyer, and Nerenz (1980)—self-regulatory model (SRM) of Illness Representation—has been found to help predict health behaviours and outcomes in patients of chronic illnesses.

The self-regulation model of illness representation (Leventhal et al., 1980) introduces a patient-centered understanding to the dynamic factors which influence health behaviours including medication adherence. Central to this model is beliefs and expectations that patients hold concerning their illness. The model suggests that, individuals, in order to understand and cope with their illness, try to make sense of their illness by developing a working framework of what their illness is, which in turn influences actions that are taken in response to the illness. The patients thus use these beliefs and expectations in interpreting the illness or to make sense of the associated somatic symptoms, deciding on a response, and evaluating the appropriateness of the response (Cameron & Leventhal, 2003).

The SRM model suggests that, although a patient's behaviour may not necessarily be medically rational, their health responses are usually informed mostly by their beliefs and expectations concerning the illness (Reynolds, 2003). These representations are however said to vary across diseases and are formed through personally experienced symptoms and information through social and cultural channels (Hirani & Newman, 2005; Hagger & Orbell, 2003). Therefore research findings related to illness representation in a particular illness condition or setting may be different from other illness groups as well as different cultural settings.

Research on chronic conditions has found that illness representations account for a significant variance in the diversity within disease-related functioning (Hirani & Newman, 2005; Horne & Weinman, 2002; MacInnes, 2013; Petrie, Weinman, Sharpe, & Buckley, 1996). Jacobs, Kemppainen, Taylor, and Hadsell (2014) assessed personal beliefs about the causes and meaning of having diabetes among the members of the Lumbee Indian tribe living in rural southeastern North Carolina. The findings indicated that higher scores on the consequence and emotional representation were associated with higher adherence to medication. However, no significant age and gender differences were found. Similarly, Ross, Walker, and MacLeod (2004) observed among hypertensive patients that emotional representation was negatively associated with compliance with medication, whereas lower consequence, lower personal control beliefs, and high-treatment control beliefs were found to be associated with high compliance with medication. Also Mosleh and Almalik (2016) explored similar concepts in a study among coronary heart disease patients in Jordan. The study showed personal and treatment control as independent predictors of medication adherence among coronary heart disease patients.

Therefore, evidence from previous studies demonstrates that there is no unitary representation for all illnesses due to differences in illness experience and differences in the cultural and social context within which a disease is experienced. It can be deduced from the foregoing reviewed literature that even though patient's adherence to anti-diabetic medication has been found to be disturbingly low in Ghana (Jambedu, 2006), and the illness practices of patients have generally not received enough research attention, studies exploring diabetes patients' own representation of the illness and how this influences medication adherence in particular is lacking. Thus, this study seeks to address this knowledge gap by quantitatively exploring the relationship between illness representation and medication adherence among diabetes patients in Ghana. Specifically, this study sets out to explore:

- (1) The components of illness representation that significantly predict medication adherence in diabetes patients.
- (2) The key demographic variables (i.e. age, education, gender, religious affiliation, duration of illness) which significantly predict medication adherence among diabetes patients.

2. Methods

2.1. Research setting

According to Guariguata et al. (2014), the current annual prevalence rate of diabetes is 3.4% affecting persons aged between 20 and 79 years in Ghana. However, the crude prevalence of diabetes in a study by Amoah, Owusu, and Adjei (2002) in Accra (the site for this study), the capital city of Ghana, was reported to be 6.3%, indicating a comparatively higher prevalence rate than the national rate.

2.2. Participants

One hundred and ninety-six diabetes patients were purposively and conveniently sampled from the out-patient unit of a tertiary hospital in the Greater Accra region of Ghana. This sample size was deemed adequate based on the statistical test proposed for the study—regression analysis for testing a medium size effect with a power of 80%. According to Tabachnick and Fidell (2007), to test an overall regression model a sample size of $50 + 8(K)$ is needed, where K is the number of predictors and so the needed sample size was 149 minimum. Again, to test independent predictors, a sample size of $104 + K$ is needed, which is less than 196 recruited for our study. Participants included in the present study had been on oral anti-diabetic medication since at least the past six months preceding the study. The sample consisted of 80 males and 116 females, all aged between 25 and 90 years old with a mean age of 59.8 (SD = 11.97) years. The number of years that participants had lived with diabetes ranged from 1 year to 40 years with a mean duration of 9.58 (SD = 8.02) years. Other demographic characteristics of the sample are shown in Table 1. Participants were included if they were 18 years of age or above, have been on anti-diabetic medications for not less than six months, and consent to participate in the study.

2.3. Measures

The participants responded to two self-report standardised scales: the illness perception questionnaire-revised (IPQ-R), and the medication adherence report scale (MARS-5). IPQ-R was employed to measure illness representation, whereas MARS-5 was used to assess the patients' medication adherence behaviour. The IPQ-R was developed to measure and assess patients' beliefs and expectations about their illness (Moss-Morris et al., 2002; Weinman, Petrie, Moss-Morris, & Horne, 1996). The IPQ-R has 71 items divided into 12 subscales with responses on a Likert format ranging from 1 (strongly disagree) to 5 (strongly disagree). However, in the present study, five of the subscales were not used due to the constraints of the cross-sectional design employed. Thus, seven subscales were used in the present study: *treatment control* which measures an individual's believe in the ability of their diabetic medication to control the disease made up of five items (e.g. my treatment will be effective in curing my diabetes); *personal control* which measures the individuals believe in their ability to alter the course

Table 1. Demographic data of sample

| Variable | | <i>n</i> | % |
|------------------------|-----------|----------|------|
| Gender | Females | 80 | 40.8 |
| | Males | 116 | 59.2 |
| Religious affiliation | Christian | 175 | 89.3 |
| | Muslim | 21 | 10.7 |
| Educational background | Low | 62 | 31.6 |
| | Middle | 73 | 37.2 |
| | High | 61 | 31.1 |

of their illness made up of six items (e.g. There is a lot which I can do to control my diabetes); *consequence* which constitutes the individuals appraised impact of their illness on their life, made up of six items (e.g. My diabetes is a serious condition); *timeline cyclical* which assesses the individuals understanding of the nature of their symptoms of their illness measured with four items (e.g. My diabetes symptoms come and go in cycles); *timeline acute/chronic* measures the individual's believe in whether their illness will be for a while or forever, made up of six items (e.g. My diabetes will last a short time); *illness coherence* which assesses the individual's perceived understanding of what their illness is, which is made up of five items (e.g. I don't understand my diabetes) and *emotional representation* measuring the emotions that are experienced when one thinks about their illness, also made up of six items (e.g. When I think about my diabetes I get upset). These components showed good test-retest reliability in other studies, with correlations ranging from .46 to .88 and internal reliability or Cronbach's alphas for the original English version of IPQ-R ranging from .79 to .89 for the subscales (Moss-Morris et al., 2002). The current study recorded Cronbach's alphas ranging between .71 and .92.

The MARS-5 (Horne & Hankins, 2004) is a 5-item self-report measure for the assessment of medication adherence (or non-adherent) behaviour. It has a 5-point Likert scale response format, ranging from 1 (very often) to 5 (never). Examples of items on the scale include "I alter my dose", "I use my medication less than is prescribed" etc. A lower score on the scale indicates lower levels of adherent behaviour to medication. Cronbach's alpha for MARS-5 reported by Bäck, Sundell, Horne, Landén, and Mårdby (2012) was .66. The Cronbach's alpha of MARS-5 for this study was .86.

The participants also reported on their age, sex, religious affiliation, number of years lived with the disease and their level of education. However, the questionnaire was anonymous in that it contained no item eliciting personal or identifiable information from participants (e.g. names, date of birth, postal or residential address, telephone number etc.).

2.4. Procedure

The study received ethical approval from the University of Ghana Ethics Committee for the Humanities (ethical clearance code: ECH 067/14-16). Permission was sought from the Ghana Health Service and the administration of the selected hospital for the study. Potential participants were walked through the purpose and general information about the study at the out-patient department where patients were waiting to see medical professionals for medication fill-up. Interested patients signed a consent form prior to participation. The questionnaires were administered individually by the researchers to the participants in a conference room designated for the study. To further strengthen anonymity and confidentiality, the sitting arrangement was spaced far apart such that a participant could not see the responses of others.

2.5. Statistical analysis

The data was analyzed using the statistical package for social sciences (SPSS, version 21). Prior to conducting the main analyses, the data were screened for statistical outliers (scores on key variables ± 3 SD from the mean). Next, correlation analyses were conducted to examine the bivariate associations among the study variables. Following this, variables with significant correlations were included in a hierarchical multiple regression analysis to test whether illness representation variables predicted medication adherence whilst controlling for the effects of demographic variables.

3. Results

3.1. Relationship between study variables

The correlations among the illness representation subscales, demographic variables and medication adherence are presented in Table 2.

Table 2. Pearson moment product correlation matrix among the study variables

| Variable | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
|----------------------|--------|--------|--------|--------|--------|------|------|---|
| 1. Acute/chronic | - | | | | | | | |
| 2. Cyclical | -.19 | - | | | | | | |
| 3. Personal control | -.31** | -.04 | - | | | | | |
| 4. Consequence | .27** | .15 | -.41** | - | | | | |
| 5. Emotional control | .01 | .25** | -.31** | .37** | - | | | |
| 6. Treatment control | -.48** | -.06 | .44** | -.19** | -.07 | - | | |
| 7. Illness coherence | .16 | -.64** | .06 | -.06 | -.25** | .16* | - | |
| 8. Adherence | -.18 | -.01 | .60** | -.50** | -.43** | .14* | -.03 | - |

* $p < .05$

** $p < .01$.

Higher illness consequence [$r = -.50, p < .01$] and negative emotional representation [$r = -.43, p < .01$] were negatively correlated with medication adherence. However, higher personal control [$r = .60, p < .01$] and treatment control [$r = .14, p < .05$] beliefs were positively correlated with medication adherence. The dimensions of illness coherence [$r = -.03, p > .05$] and disease timeline chronicity [$r = -.18, p > .05$] and timeline cyclical [$r = -.01, p < .05$] were not significantly correlated with medication adherence.

3.2. Predictors of medication adherence

The overall regression model predicting medication adherence from patient demographic variables and illness representation components using a hierarchical multiple regression was significant [$R^2 = .516, F(12,183) = 16.25, p < .01$] explaining about 51.6% of variance in the level of medication adherence among this sample (see Table 3).

From the Table 3, in step 1, where the demographic variables were entered, the regression model was not significant [$R^2 = .014, p = .05$, step 1]. Thus, generally, all the demographic variables did not independently account for any significant variance in medication adherence. In step 2 of Table 3, illness representation components were entered, and this yielded a significant regression model [$\Delta R^2 = .502, p < .01$, step 2]. Thus, all the illness representation components in general accounted

Table 3. Hierarchical multiple regression of Medication adherence

| Predictors | B | SEB | β | t | p | ΔR^2 |
|--------------------------|------|-----|---------|-------|-------|--------------|
| Model 1 | | | | | | .014 |
| Age | .01 | .01 | .06 | .96 | .33 | |
| Illness duration | .03 | .02 | .09 | 1.55 | .12 | |
| Gender | .25 | .34 | .04 | .74 | .45 | |
| Religion | .22 | .45 | .03 | .48 | .63 | |
| Education | .26 | .30 | .05 | .89 | .38 | |
| Model 2 | | | | | | .502** |
| Acute | -.01 | .04 | -.01 | -.16 | .88 | |
| Cyclical | .04 | .09 | .03 | .43 | .67 | |
| Personal control | .47 | .06 | .48 | 7.85 | .00** | |
| Consequence | -.23 | .05 | -.29 | -4.67 | .00** | |
| Emotional representation | -.10 | .03 | -.21 | -3.52 | .00** | |
| Treatment control | -.11 | .07 | -.10 | -1.52 | .12 | |
| Illness coherence | -.08 | .05 | -.11 | -1.58 | .12 | |

Note: $R^2 = .02, (p > .05)$ for Step 1; $\Delta R^2 = .502, (p < .01)$ for Step 2; ** $p < .01$ alpha level.

50.2% of the variance in medication adherence. As shown in Table 2, the illness representation components that were independently related to medication adherence in this sample were *representation of personal control* [$\beta = .48, t = 7.58, \rho < .01$]; *representation of consequence* [$\beta = -.29, t = -4.67, \rho < .01$]; and *emotional representation of the illness* [$\beta = -.21, t = -3.52, \rho < .01$].

4. Discussion

This study set out to investigate whether illness representation and patient demographics are predictors of medication adherence among diabetes patients in Ghana using a sample of 196 diabetes patients from a tertiary Hospital in the Greater Accra Region. The findings indicated that, none of the patient demographic variables measured (i.e. age, gender, religion, educational background and duration living with the illness) was significantly related to medication adherence. The illness representation component of the personal control subscale was independently and positively related to medication adherence, whilst illness consequence and emotional representation were independent negative correlates of medication adherence.

Thus demographic variables (age, gender, religion, educational background and illness duration) did not predict a significant variance in medication adherence. This finding is consistent with the evidence by Jacobs et al. (2014) who found no significant differences for age (over or less than 50 years) or gender among a sample of diabetes patients in India. Horne and Weiman (2002) found that, socio-demographic and clinical factors explained only a small amount of variance in adherence. As such categorising or targeting demographic variables for interventions may not be beneficial to diabetes patients.

Drawing on these findings, overall, the components of illness representation with significant independent relationship with medication adherence are *personal control*, *illness consequence* and *emotional representation*. In other words, diabetes patients who believe that they can personally engage in activities to alter the course of their illness are likely to adhere to their prescribed medication. However, patients who believe diabetes has serious negative impacts on their lives and represent it with negative emotions are less likely to adhere to their prescribed medication. This current finding is consistent with some previous studies, however, the variables vary as to which of the components positively or negatively predicted medication adherence. For instance, in the study by Jacobs et al. (2014) from Indian, the findings indicated that higher scores on the consequence and emotional representation were associated with higher adherence to medication. However, in a similar study by Ross et al. (2004) emotional representation was negatively associated with compliance with medication while lower consequence, lower personal control beliefs, and high-treatment control beliefs were associated with higher compliance. Also, Mosleh and Almalik (2016) found that personal and treatment control were positive independent predictors of medication adherence. The findings of the present study suggest that having higher beliefs of negative illness consequence, the representation of the disease with negative emotions, and the belief that one can alter the course of the disease through their own initiatives positively predicted medication adherence.

This could be explained with the learned helplessness theory (Maier & Seligman, 1976) which suggests that individuals who experience severe stressful situations over a period of time in turn learn that nothing can be done about their condition and thus give up trying to deal with the situation. As regard low medication adherence observed in this study, it can be argued that, people who experience negative diabetes consequences over a long period of time tend to adhere less to their prescribed medication plausibly because they tend to subscribe to the false belief that the impact of diabetes on their lives will persist for a lifetime regardless of medication adherence. Also studies exploring illness practices in Ghana among patients living with diabetes have identified that although most patients rate biomedical management as the preferred practice, they are constrained due to the psychosocial impact of the disease, hence driving them to other practices such as cure seeking and medical inaction (Aikins, 2005). Likewise, when patients perceive that taking their medication will alter their state of wellbeing with some form of side effect from the medication that can

alter their daily living, the patients are unlikely to continue taking the medication even though medication helps in managing the diagnosed condition (Read, 2012).

Finally, it is evident from this study that, personal control belief is positively related to medication adherence. This means that, patients with the belief that they are able to do something to alter the course of their chronic health condition are more likely to adhere to their prescribed medication. Rozema, Völlink, and Lechner (2009) found that personal control had a significant positive relationship with problem-focused coping. Medication adherence in this study can be described as a form of problem-focused coping where patients take active measures to control their diabetes. This finding is consistent with the theory of planned behaviour which supposes that perceived behavioral control has a direct influence on intention, and that for desirable behaviours, greater perceived behavioral control is needed (Kraft, Rise, Sutton, & Røysamb, 2005).

5. Research implication

The study has some implications for healthcare delivery to diabetes patients by health professionals providing care. The findings of the study give support to the fact that a patient's cognitive and emotional appraisal of their chronic illness is important in the management of chronic illness. The study implies that patients have their own beliefs and expectations about their condition, aside what they are told by health professionals. The health beliefs and expectations held by patients have been shown to relate to the rate at which they adhere to their prescribed medication as well as their level of psychological distress. The evidence from this study further implies that key attention should be paid by health professionals to the representation of diabetes by patients, as previous evidence shows that patients' illness representation significantly relates to the level of medication adherence. The results of the current study show that, diabetes patients, who doubt their ability to control their illness, represent higher disease consequence and hold higher levels of negative emotions about the disease are less likely to adhere to their recommended medications. Interventions should thus be directed at empowering patients to take maximum control over their illness believing that their actions could improve their condition above their disease consequence expectations. It is thus imperative for health professionals to be holistic in their approach to healthcare by taking into consideration the importance of the patients' representation of the disease, while providing care for diabetes patients.

6. Limitations

A notable shortcoming of the present study which should guide the interpretation and conclusions drawn relates to the inability of the study to adequately explore all potential (and contextually relevant) factors which could be related to medication adherence in diabetes patients in Ghana (age, sex, duration since diagnoses, religious affiliation, etc.). Given the paucity of studies on medication adherence among diabetes patients in low and-middle-income countries, including Ghana, future studies may consider the use of qualitative approaches to explore other factors and contextually relevant variables (e.g. medication affordability, spirituality, side effect of medication etc.) which may influence patient behaviour in terms of diabetes medication adherence. Another plausible limitation is the sample source and characteristics. The participants in this study were selected from one hospital, limiting the generalizability of the findings. Again, the study used diabetes patients who could communicate in the English language thereby excluding non-English speaking participants who could have otherwise provided other potentially interesting responses. Finally, the cross-sectional design precluded establishing causal relationship between living with diabetes and, medication adherence and illness representation variables.

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Competing interests

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