ILLNESS PERCEPTIONS AND MEDICATION ADHERENCE IN ADOLESCENTS WITH SICKLE CELL DISEASE IN TWO SELECTED HOSPITALS IN GREATER ACCRA

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Abstract

Some previous researches in the West and Europe have indicated how illness perceptions relate to medication adherence in adolescents with various chronic diseases. There is however a gap in the literature on how the various illness perception dimensions are associated with medication adherence in Ghana among adolescents with chronic diseases like sickle cell. The aim of this study was to investigate how the various illness perception dimensions are associated with medication adherence in adolescents with sickle cell disease. A total of 120 adolescents' sickle cell patients receiving treatments at Korle-Bu Teaching Hospital and Tema General Hospital were conveniently sampled to be part of the study. They completed self-report questionnaires about their demographic and medical data, their illness perception using the Illness Perception Questionnaire-Revised (IPQ-R) and their medication adherence using the Medication Adherence Report Scale-5 (MARS5). The outcome of the analysis using the Pearson Product Moment Correlation Coefficient indicated a significant positive relationship between the following illness perception dimensions (consequences, emotional representation, treatment control, timeline cyclical, timeline-acute/chronic and illness coherence) and medication adherence. The multiple regression analysis indicated that timeline cyclical significantly predicted medication adherence the most compared to the other dimensions. The findings of this study provided evidence that illness perception of adolescents with sickle cell disease is significantly related to medication adherence. Health care providers such as nurses and doctors should consider having a discussion about the perception adolescents with sickle cell disease have about their condition as this is related to medication adherence. Also, when treatment is been planned, it should be tailored to meet the individual needs.

Keywords: Illness perceptions, Medication adherence, Sickle Cell Disease (SCD)

Background

Sickle cell disease (SCD) also known as sickle-cell anaemia or sickle cell disorder is a genetically inherited blood disorder that causes red blood cells to become sticky and sickle in shape. It is one of the most common but preventable genetic diseases. One is diagnosed with sickle cell disease when the person inherits two sets of abnormal recessive genes (e.g. Hb S and S or C, D, E or β thalassaemia) one from each parent. In Ghana, about 25,000 SCD children and adults have been registered with the sickle cell clinic at Korle-Bu Teaching Hospital (Adult Sickle Cell Clinic Records, 2011). Also 2% of children born every year have SCD and about 25% to 30% of Ghanaians are carriers of SCD (Ohene-Frempong, Oduro, Tetteh & Nkrumah, 2008). Having a sickle cell disease comes with some complications or challenges such as serious infections, damage to vital organs, stroke, kidney damage, respiratory problems, bone marrow failure, growth failure, cognitive impairment, maturational delay in children as well as high maternal and foetal morbidity and mortality (Zemel, Kawchak, Ohene-Frempong, Schall & Stallngs; Ocheni, Onah, Ibegbulam & Eze, 2007).In addition, individuals with sickle cell disease also manifest acute and chronic pain in their bones and joints. Acute pain which is the most predominant symptom can be very severe and can last from hours to days. The painful crisis is the most distressing symptom in patients with SCD (Wethers, 2000). Sickle cell disease is a chronic condition and patients are expected to adhere to various treatment or management plans to cope with their conditions. This is not usually the case for most patients.

Non-adherence has been identified in the literature as one of the barriers to the prescription of Hydroxyurea for SCD (Brandow, Jirovec & Panepinto, 2010). Non-adherence to treatment regimen is a problem which undermine the benefits of current medical care (Hand & Adams, 2002). Many factors contribute to non-adherence including: patients not understanding instructions given about treatment or medication, inability to afford cost of treatment, perceptual factors such as patients' beliefs, and their preferences which determine their motivation to adhere to treatment. Adherence among adolescents has been found to be a more challenging task because adolescence is a period of development when long-standing health care behaviours are established (Greening, Stoppelbin & Reeves; Williams, Holmbeck & Greenley, 2002). Research has shown that many patients with various pediatric chronic conditions have difficulty adhering to their recommended regimen (Kahana, Drotar &Fraizer, 2008; Quittner, Modi, Lemanek, Ievers-Landis, Rapoff, 2007).

The self-regulation model proposes that how an individual cognitively represents his/her illness is a determinant of how the person will cope or adhere to treatment (Leventhal, Nerenz & Purse, 1984). The SRM has many dimensions along which a person conceptualizes his or her illness. The identity dimension refers to the label given to the

illness, timeline acute or chronic is the patients belief about how long or short the illness will last, consequences measures a patients perception of the possible effects of the illness on their life. The control dimension looks at how a patient represents illness in terms of whether they believe the illness can be treated or cured (treatment control) and whether the outcome of their illness is within their capacity to be controlled by themselves or to be controlled by another person (personal control). The illness coherence dimension is interested in finding out the extent to which patients have a clear understanding of their illness. The emotional representation dimension attempts to measures the patient's emotional reactions to the illness. The timeline cyclical is interested in whether patients perceive their condition to be recurring.

Several research with different illness groups such as chronic renal failure, diabetes, and hypertension have provided evidence to support the assertion that illness belief or perception is a significant framework for explaining the ability of the patients to cope and for developing interventions to prompt self-management in chronic disease (Baroletti & Dell'Orfano, 2010; Petrie & Weinman, 2012; Hale, Treharne & Kitas, 2007). In one study, it was realized that asthmatic patients adhered well to treatment when the treatment regimen made sense to them and when the patients felt they had the ability to succeed at the regimen (Hand & Adams, 2002). In another related study, a significant relationship between illness coherence and adherence was also seen. (Molloy et al., 2009). Some illness beliefs dimensions (emotional responses, perceived consequences, cure/control) were also found to be predictors of adherence among adults with hypertension (Ross, Walker &MacLeod, 2004). A significant relationship between timeline, consequences, personal control, coherence, concern and exercise adherence was also reported in another research (Mosleh & Almalik, 2016). Perceived controllability of illness was also found to be related to adherence across different conditions in their meta-analysis (Hagger & Orbell, 2003). Research has also found a significant relationship between emotional representation and adherence (Žugelj et al., 2010), a significant positive relationship between timeline acute/chronic and medication adherence (Nicklas, Dunbar & Wild, 2010; Aflakseir, 2012; Massey et al., 2013) and a significant relationship exist between treatment control and medication adherence (Griva, Myers & Newman, 2000; Senior, Marteau, Weinman & Genetic Risk Assessment for FH Trial study Group, 2004). Some other researchers found timeline cyclical to be a significant predictor of medication adherence (Platt, Green, Jayasinghe & Morrissey, 2014). Among patients with non-malignant chronic pain, their perception of illness as uncontrollable was significantly related to medication adherence (Nicklas, Dunbar & Wild, 2010). Similarly participants who had lower personal control reported higher levels of adherence (Turrise, 2016).

The main aim of this study was to investigate the relationship between illness perception and medication adherence among adolescents with sickle cell disease. The psychological

explanations of adherence in adolescents with sickle cell disease has been understudied and researches are needed to help fill this gap in the literature. In Ghana, the few studies done in the area of medication adherence used adult population (Bruce, Acheampong &Kretchy, 2015; Ankrah, Lartey, Agyepong, Leufkens, Mantel-Teeuwisse, 2015). The findings of this study will be useful to other researchers interested in doing research in the area of illness perception and adherence among adolescents with various chronic conditions. The study will also be useful for clinical practitioners in developing effective treatment plans for adolescents.

Objective of the study
The main aim of this study was to investigate the relationship between illness perception and medication adherence among adolescents with sickle cell disease.

Hypotheses
Based on previous studies, it was hypothesised that the following illness perception dimensions (consequences, emotional representation, treatment control, timeline cyclical, timeline acute/chronic, illness coherence, personal control) will be related to medication adherence.

Methodology
Research Design
A cross sectional survey of adolescents with sickle cell disease was conducted between April, 2015 to June, 2015.

Participants and Setting
The sample for this study was one hundred and twenty (120) adolescents with sickle cell disease who were conveniently sampled whiles seeking for treatment at the out-patients sickle cell clinics of Korle-Bu Teaching Hospital (KBTH) and Tema General Hospitals (TGH). These hospitals were selected because they are the two major public health facilities that run sickle cell clinics in Accra. Accra is the capital town of Ghana and it is cosmopolitan in nature as it has people of both rural and urban backgrounds.

Participants were included in the study if they were receiving treatment for at least a month at any of these facilities from April, 2015 to June 2015 as a result of a confirmed diagnosis of sickle cell disease by a health-care professional. Participants were excluded if they were more than 19 year old.

Procedures
The research was approved by the University of Ghana Ethics Committee for Humanities. Permission was also obtained from the Greater Accra Regional Health

Directorate of the Ghana Health Service to collect data from the two hospitals. The lead author together with one research assistant who was trained to administer the questionnaires collected data from the participants at the hospital whiles they were waiting to be attended to by the doctor or nurse or after their medical consultation. For participants who were below 18 years, consent was sought from their parents or an adult who accompanied them to the hospital. However, for those who were 18 years and above, informed consent was sought from them and the questionnaires were administered. The questionnaire was paper-based and it was self-administered to participants who could read and write English. For those who could not read nor write in English, the lead author and the trained research assistant assisted them to complete the questionnaires by translating the questionnaires into Akan (a local language that they all understand). Before the questionnaires were given to them, the purpose of the study was made known to them, the benefits they were likely to get from participating in the study were also made known to them. They were also given the opportunity to ask questions before they proceed to respond. Participants were assured of anonymity and confidentiality of information provided. In all it took approximately 25 minutes to complete the questionnaires.

Measures
The Revised Illness Perception Questionnaire-IPQ-R
The Revised Illness Perception Questionnaire (Moss-Morris et al., 2002) was used to assess participants' perception of their illness along the dimensions of timeline acute or chronic (6 items (e.g. My sickle cell illness will last a short time), illness coherence (5 items (e.g. I don't understand my sickle cell illness), timeline cyclical (4 items (e.g. My sickle cell symptoms come and go in cycles), treatment control (5 items (e.g. My treatment will be effective in curing my sickle cell illness), personal control (6 items (e.g. There is a lot which I can do to control my sickle cell illness), emotional representation (6 items (e.g. When I think about my sickle cell illness I get upset), and consequences (6 items (e.g. My sickle cell illness is a serious condition). The scale was modified so that illness as stated on the original scale was replaced with "sickle cell illness". These items are scored on a Likert scale ranging from strongly disagree =1, disagree= 2, neither agree nor disagree=3, agree= 4 to strongly agree=5. Research shows that the Revised Illness Perception Questionnaire (IPQ-R) is a valid measure of illness perception (Knibb & Horton, 2008). The components of the scale showed a good test-retest reliability, with correlations ranging from .46 to .88 and internal consistency 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 authors suggested that a high score on the timeline, consequences, and cyclical dimensions show patients belief about the number of symptoms attributed to their illness, the chronicity of the condition, the negative consequences of the illness and the cyclical nature of the condition respectively. High scores on the personal control,

treatment control and coherence dimensions gives an impression that participants have positive beliefs about the controllability of the illness and a personal understanding of the condition. Items 1,4,8,15,17,18,19,23,24,25,26,27,36 are reverse scored accordingly.

Medication Adherence Report Scale 5 (MARS-5)

The inventory Medication Adherence Report Scale (Horne & Hankins, 2004) is 5-item self-report scale for assessment of adherent and non-adherent behaviour. The items are rated on a 5-point Likert scale, ranging from 1= 'very often to' 5 = 'never'. Examples of items include "I take less than instructed" and I sometimes forget to take my medicines." Lower scores indicate lower levels of adherent behaviour and higher scores indicate higher levels of adherence. It was used to measure participant's self-reported adherence to their sickle cell illness medication Scores range from 5 to 25. Cronbach's alpha for MARS was 0.77 (Menckeberg, 2008).

Demographic characteristics

Age (continuous), gender, duration of sickle cell since diagnoses (years), educational background (primary, secondary, tertiary), religious status (Christian, Islam, others) and type of sickle cell were all self-reported.

Statistical analysis

All data was analysed using IBM SPSS version 20.0. Variables such as gender, religion, sickle cell genotype, educational level, age were reported as frequencies and percentages. Means were used to describe the duration of illness. Pearson correlations was used to ascertain the relationship between the various illness perception dimensions and medication adherence. The multiple linear regression was employed to ascertain which of the illness belief dimensions was accounting for variance in medication adherence the most.

Results

Demographic Data of Participants

Of the 135 potential participants approached, 130 (96%) were eligible. Others were ineligible because they were too sick to participate. Of those eligble, 120 (92%) completed their questionnaires appropriately. The demographic characteristics are presented in Table 1. The sample included 60 (50%) males as well as 60 (50%) females. Out of the 120 adolescents sampled, 46 (38.3%) were between the age range of 13 to 16 years and the remaining 74 (61.6%) were between the ages of 17 to 19 years. 42 (35.0%) indicated that their current level of education was Primary, 51(42.5%) were at the Secondary Level and 27(22.5%) were at the Tertiary level. For religious affiliation, 101 (84.2%) were Christians, 16 (13.3%) were Muslims and the remaining 3 (2.5%) indicated other religion. For SS as a genotype of Sickle, 49 (40.8%) indicated, that was their status.

The majority (n=68 (56.7%) indicated having SC as their genotype. The remaining 3(2.50%) participants indicated other genotypes.

Table 1: Demographic Characteristics of the Sickle Cell Patients

Characteristics	F (%)
Gender	
Male	60 (50.0%)
Female	60 (50.0%)
Age	
13-16 years	46 (38.3%)
17-19 years	74 (61.6%)
Education Background	
Primary	42 (35.0%)
Secondary	51 (42.5%)
Tertiary	27 (22.5%)
Religion	
Christianity	101 (84.2%)
Islam	16 (13.3%)
Others	3 (2.5%)
Type of Sickle Cell	
SS	49 (40.8%)
SC	68 (56.7%)
OTHERS	3 (2.5%)
Duration of Illness (Mean)	2.75

Relationship between illness perception dimensions and medication adherence.

Table 2 is a representation of Pearson Product-Moment correlation coefficients to find out if there was any significant positive relationship between six illness perception dimensions (consequences, emotional representation, timeline acute and chronic, timeline cyclical, treatment control, illness coherence) and medication adherence which were all continuous variables and measured on at least interval scale. From the correlation matrix in table 2 presented below, it was observed that illness consequences was positively and significantly related with medication adherence ($r_{(120)} = .45$, $\rho < .01$). A significant positive relationship was also obtained between emotional representation and medication adherence ($r_{(120)} = .90$, $\rho < .01$). A significant positive relationship was again observed between timeline acute/chronic and medication adherence (($r_{(120)} = .82$, $\rho < .01$). It was again observed that a significant positive association existed between timeline cyclical and medication adherence ($r_{(120)} = .87$, $\rho < .01$). Treatment control ($r_{(120)} = .77$, $\rho < .01$) and illness coherence ($r_{(120)} = .76$, $\rho < .01$) dimensions were also significantly related to medication adherence. A significant but negative relationship was however obtained between personal control and medication adherence ($r_{(120)} = -.62$, $\rho < .01$).

Table 2: Bivariate Correlation between Illness perception and Medication Adherence

VAR	1	2	3	4	5	6	7	8
1.MARS	-							
2.TLC	.87**	-						
3.TL	.82**	.72**	-					
4.TC	.77**	.68**	.71**	-				
5.ER	.90**	.82**	.84**	.74**	$.03^{ns}$	-		
6.CON	.45**	.33**	.42**	*42**	$-.08^{ns}$	.48**	-	
7.IC	.76**	.64**	.68**	.64**	$-.07^{ns}$	.79**	.46**	-
8.PC	-.62**	-.64**	-.62**	-.59**	$.01^{ns}$	-.65**	-.28**	-.49**

**Significant at .01 alpha level, *Significant at .05 alpha level. TL=Timeline (acute/chronic), TLC= Timeline Cyclical, TC= Treatment Control, ER=Emotional Representation, CON= Consequences, IC=Illness Coherence, PC= Personal Control, MARS=Medication Adherence Report Scale, ns=not significant.

Multiple Linear regression indicating the contribution of each of the illness perception dimensions to medication adherence.

A multiple linear regression analysis was done to find out how the various dimensions of the illness belief scale are associated with medication adherence or explain the amount of variation in medication adherence among adolescents with sickle cell disease after age, education, gender, duration of illness, type of sickle cell were controlled for. The results as presented in Table 3 indicated that, in step 1 when the control variables alone where entered, there was a significant R square [R^2=.12, $F_{(6,113)}$ =2.517, ρ<.05]. In step 2 when the various illness belief dimensions were entered, the results showed that there was a significant R squared change [R^2=. 78 $F_{(8,105)}$ =95.66, ρ<.001]. The contributions of each of the illness belief dimensions in explaining the variance in treatment compliance are summarised and presented in the Table 3.

A careful observation of Table 3 showed that the most significant illness belief dimension that associated with medication adherence was timeline cyclical which contributed positively to 34% of variance in medication adherence [β=.34,t=5.60,ρ<.001]. The second most significant dimension associated with medication adherence was emotional representation which also contributed positively to 33% of variance in treatment compliance [β=.33, t=3.90, ρ<.001]. The third significant dimension associated with medication adherence was the belief about illness as timeline acute or chronic which contributed positively to 14% of variance in treatment compliance [β=.14,t=2.70, ρ<.05]. The fourth significant illness belief dimension associated with medication adherence was the perception of treatment control about the sickle cell illness which contributed positively to 13% of variance in medication adherence [β=.13, t=2.47, ρ<.01]. The fifth

significant dimension associated with medication adherence was illness coherence which contributed positively to 11% of variance in treatment compliance [β=.11, t=2.00, ρ<.05].

Table 3: **Multiple Linear Regressions of the contributions of the illness belief dimensions to Medication Adherence**

Predictors	B	SEB	β	T	P
Step 1					
Constant	20.87	3.5		6.01	.000
Age	.13	.24	.07	.53	.599
Duration	-.22	.21	-.14	-1.06	.292
Education	-.71	.40	-.17	-1.79	.076
Sex	.65	.60	.10	1.08	.283
Religion	-.42	.68	-.56	-6.2	.535
Genotype	1.3	.55	.21	2.37	.020
Step 2					
Personal Control	.03	.03	.04	.857	.393
Treatment Control	.19	.07	.13	2.47	.015
Illness Coherence	.13	.06	.11	2.00	.048
Emotional Representation	.24	.06	.33	3.90	.000
Timeline Cyclical	.37	.07	.34	5.60	.000
Consequences	.01	.05	.004	0.93	.926
Timeline (Acute and Chronic)	.13	.06	.14	2.27	.025

Independent Variables: Personal Control, Treatment Control, Illness Coherence, Emotional Representation, Timeline Cyclical, Consequences, Timeline (Acute and Chronic)
Dependent Variable: Medication Adherence

Discussion

This is the first study in Ghana to examine whether illness perceptions are significantly related to medication adherence in adolescents with sickle cell disease. Correlation was done and the results of the analysis indicated that all the illness perception dimensions were significantly related to medication adherence. This means that participants in this study perceived their sickle cell illness to have negative consequences on them and their adherence to medication was high. This finding is consistent with findings in other researches (Ross, Walker & MacLeod, 2004; Mosleh & Almalik, 2016). A possible reason for the significant positive relationship seen between illness consequence and medication adherence in this study may be attributed to the concept of consequences. Illness consequences is defined in this study as the patient perception of the effects of the illness on their life. Consequences may be physical, emotional, or several other

interacting factors (Ogden, 2012). The consequences are perceived as something that is likely to happen now or in the future. Considering the fact that the participants in this study are adolescents and they possibly have many years to live before they die, they perceive serious consequences for their illness in the future, thus, their adherence to medication to reduce the negative consequences associated with their illness. It is also possible that despite the adolescents being young, they may have already experienced serious consequences of living with sickle cell disease and this might have shaped their illness management behaviour hence their adherence to medication in the present. A significant positive relationship was also observed between emotional representation and treatment compliance. This means that as participants perceived their illness to have negative impact on their emotion's the more likely they are to comply with treatment. Higher emotional representation of sickle cell disease gives the indication that the disease induces high negative feelings such as fear, anger and sadness which are all negative. The finding was consistent with some past research (Ross, Walker & MacLeod, 2004; Žugelj et al., 2010; Abubakari et al., 2011). A significant positive relationship was also observed between timeline acute and chronic and medication adherence. This means that as participants perceive their condition to be chronic, the more adherent they become to medication and if they perceive it to be acute, they less adherent they will be since they are of the view that their illness will not last long. These findings were consistent with some studies done by other researchers (Ogden, 2012; Aflakseir, 2012; Massey et al., 2013). Again, a significant and positive relationship was observed between timeline cyclical and treatment compliance. The belief of sickle cell as cyclical in nature by participants in this study means that they see their condition and symptoms associated with it to be unpredictable and changing. Seeing their condition as unpredictable and fluctuating will make them comply with treatment as they don't know when the symptoms of their condition will appear to make things difficult for them. Perceiving their condition to be cyclical in nature is evident in the pain patients frequently experience. The experience of pain which is a major symptom experienced by sickle cell patients is not predictable thus their perception of their condition as cyclical. This finding was consistent to that which was found in other studies (Nicklas, Dunbar, Wild, 2010; Maclnnes, 2013).

A significant and positive relationship was also seen between treatment control and medication adherence. This means that as individuals had strong beliefs that their treatment will be effective the more they will adhere to their treatment. Other researchers found similar results in the studies [Ross, Walker & MacLeod, 2004; Griva, Myers & Newman, 2000, Senior, Marteau, Weinman & Genetic Risk Assessment for FH Trial (GRAFT) Study group, 2004).Therefore adolescents patient's belief of the benefits of medication in controlling their disease can be said to be a motivational force for their continual medication adherence.

A significant positive relationship was also obtained between illness coherence and medication adherence. This is consistent with other findings by other researchers who used different poulation (Mosleh & Almalik, 2016; Maclnnes, 2013). This means is that adolescent patients with sickle cell disease demonstrate an appreciable level of understanding of their condition and this understanding of their condition as chronic or as having high negative consequences is manifested in their adherence to treatment.

To further examine whether a significant but negative relationship exists between personal control and adherence to medication, correlation was done and the results showed that there is a significant and negative relationship between personal control and medication adherence. This means that as the adolescents with sickle cell disease had the belief that they can control their illness, their adherence to medication decreases and if they believe they have no personal control over their illness, their adherence to medication increases. This hypothesis was supported in this study. This finding is consistent with the works of other researchers (Nicklas, Dunbar & Wild, 2010; Turrise, 2016). A possible explanation is that although participants felt they had control personally over their illness, they still believed that treatment would be effective in the management of their disease so they still complied with treatment. Timeline cyclical was however found to have predicted medication adherence than the other illness belief dimensions when a regression analysis was done to see which of the illness beliefs dimensions was significantly predicting treatment compliance. This hypothesis was supported. It is consistent with previous studies where timeline cyclical was found to be one of the significant predictors of adherence (Platt, Green, Jayasinghe & Morrisey, 2014).

Strengths and Limitations
This is the first study to investigate illness perception and medication adherence in adolescents with sickle cell disease in Ghana. The study also employed valid and reliable instruments for measuring the various variables. A major setback of this study was the adoption of a cross-sectional design, which makes it difficult to establish a causal link between the variables under investigation. Another limitation is the issue of the use of self-report to measure illness perception and medication adherence, making it susceptible to social desirability bias especially for medication adherence.

Implications and future research
The outcomes obtained from this study have implications for medical professionals like doctors who have direct contact with adolescents who have sickle cell disease. This study has offered support for SRM by providing evidence that illness perceptions are associated with medication adherence among adolescents with sickle cell disease in Ghana. For

Clinical or health psychologists, special attention should be paid to the illness perceptions of adolescents with sickle cell disease as the research indicated that illness perception significantly accounted for the level of adherence to medication. Qualitative Studies can also be carried out to have an in-depth exploration of how the various dimensions of illness perception affect medication adherence. Future studies should also consider doing a comparative study to compare findings with other adolescents who have other chronic conditions to find out if there any differences.

Conclusion

This research investigated the relationship between illness perceptions and medication adherence among adolescents with sickle cell disease in Ghana. All the illness perception dimensions (timeline cyclical, timeline-chronic and acute, illness coherence, treatment and personal control, emotional representation) in this study were significantly related to medication adherence. Timeline cyclical was found to be a more significant predictor of medication adherence followed by emotional representation and treatment control.

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