Caregiver's Health Locus of Control and Medication Adherence in Sickle Cell Disease

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Purpose: To explore caregivers' Health Locus of Control's relationship to self-reported adherence to penicillin prophylaxis or hydroxyurea in children with sickle cell disease (SCD).

Procedure: A questionnaire-based study was conducted of caregivers of children with SCD who visited a comprehensive sickle cell center in an inner city hospital, who were either on penicillin prophylaxis or hydroxyurea or both. Multidimensional Health Locus of Control Scale (MHLC) and the Morisky Medication Adherence Scale (MMAS-8) questionnaires were used for the study.

Results: Caregivers of 43 children (27 on penicillin prophylaxis, 13 on hydroxyurea, and 3 on both) completed the MHLC and the MMAS-8. There was no significant difference in adherence between the penicillin and the hydroxyurea groups. The mean Powerful Others score of caregivers of the hydroxyurea only group (25.5+5.6) was higher than that of the penicillin only group (21.2+6.1, p=0.043). Regression analysis revealed an inverse relationship of Chance Locus of Control to adherence in the entire group (Beta = -0.306, R2=0.093, F[1,40]=4.12, p=0.049).

Conclusion: Chance Locus of control may identify caregivers of children with SCD at risk for non-adherence to treatment.

Keywords: health locus of control ■ medication adherence ■ sickle cell disease ■ caregivers

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INTRODUCTION

Infections and vaso-occlusive crises are common causes of morbidity and mortality in sickle cell disease (SCD). Two medications are commonly used to target infections and vaso-occlusive crises, penicillin and hydroxyurea, respectively. The landmark PROPS I (prophylaxis with oral penicillin) study demonstrated that 84% of the pneumococcal infections could be prevented in children less than 5 years of age through the use of prophylactic oral penicillin.[1] The Multi-Center study of Hydroxyurea demonstrated that hydroxyurea decreased the frequency of vaso-occlusive crises, acute chest syndrome, and need for transfusions.[2]

Although both medications are effective in preventing complications of SCD, adherence remains a problem as both have to be administered daily in order to be effective. In a group of pediatric patients with SCD, compliance with penicillin prophylaxis as determined by urine assay was 43.1%.[3] In another study in children ≤ 18 years, adherence to hydroxyurea was reported as 49%, based on pharmacy refills.[4] These rates make it important to understand factors related to non-adherence.

Penicillin is given from infancy, is considered relatively benign and does not require monitoring for toxicity. Hydroxyurea is administered after the patient has experienced complications of the disease; and requires close monitoring of the blood count for leukopenia. However, since the positive clinical effects of hydroxyurea are evident in most patients, it would be difficult to predict which medication would have a higher adherence rate. Hence, it is important to compare the adherence to prophylactic penicillin and/or hydroxyurea and explore factors that may be related to non-adherence.

Factors that influence adherence to medications include route of administration, dosing schedule, and motivation of the patient/caregiver.[5] Locus of control (LOC) is a factor that influences motivation.[6,7] LOC refers to the extent to which a person expects that the outcomes in one's life are under the control of one`s own actions (internal LOC) as opposed to being controlled by outside factors (external LOC).[6] Wallston et al. developed the Multidimensional Health Locus of Control (MHLC) Scale, a modification of the traditional concept of LOC, by splitting the external locus of control into two domains, "Powerful Others" and "Chance" which would be applicable to health behavior.[7] It was based on the premise that a belief that physicians or other health care workers influence one's health is conceptually different than a belief that one's health outcome is due to luck or chance.

MHLC has three domains: Internal (the extent to which a person believes that he/she has control over his/her own health), Powerful Others External (powerful people such as physicians or other health care professionals have control over the person's health) and Chance External (health is related to fate, luck or chance and nobody has control). A person is assessed as to how high or low s/he scores in each of these three domains. Studies have been

done demonstrating MHLC's relationship to treatment adherence in other medical conditions.[8,9] One study showed that in a group of patients with hypertension, those with internal LOC adhered more to their treatment regimen than those with external LOC.[9] Another reported that caregivers who believed that health was related to chance external factors were less likely to attend appointments for stroke follow up.[8] A study of 7115 young adults from 18 European countries showed that those with higher internal locus of control were more likely to engage in healthy behavior than those with high chance scores.[10]

There is a paucity of research literature on addressing problems with LOC in the healthcare setting. One study reported that teaching autogenic relaxation training through biofeedback improved Internal LOC in adolescent alcoholics[11] and suggested that this may be an important therapeutic intervention.

In this study, we explored the role of LOC in adherence to penicillin and hydroxyurea in caregivers of children with SCD. We used the MHLC Scale and Morisky Medication Adherence Scale (MMAS-8) and tested the following hypotheses:

1 Adherence to hydroxyurea is higher than adherence to penicillin
2 Medication adherence is positively related to *Internality* in health locus of control
3 Medication adherence is positively related to *Powerful Others Externality*
4 Medication adherence is negatively associated with *Chance Externality.*

Table 1. Demographics, Adherence and MHLC[a] Scores

Group ->	Penicillin	Hydroxyurea	Penicillin & Hydroxyurea	Entire Sample
Number of Subjects	27	13	3	43
- Male	14	6	2	22
- Female	13	7	1	21
- SS Disease	19	13	3	35
- SC Disease	8			8
Age (years)[b]	2.9±1.6 (3; 0-7)	12.1±4.6 (10, 6-20)	4.3±0.6 (4; 4-5)	5.7±5 (4; 0-20)
Number of Caregivers	26[c]	13[d]	3[e]	42
Caregivers' Age (years)[b]	31.3±7.8 (30; 19-58)	37.5±7.5 (36; 21-50)	40.3±11.5 (40; 29-52)	33.8±8.5 (32; 19-58)
Adherence (MMAS-8)[bf]	6.3±1.7 (7; 4-8)	6.5±1.6 (7; 4-8)	8±0 (8; 8-8)	6.5±1.6 (7; 4-8) [g]
Internality-MHLC[b]	24.9±5.3 (24; 16-36)	23.9±5.7 (24; 12-34)	25.3±6.1 (24; 20-32)	24.6±5.4 (24; 12-36)
Powerful Others Externality-MHLC[b]	21.2±6.1 (21.5; 10-33)	25.5±5.6[h] (26; 14-33)	24±10.6 (28; 12-32)	22.7±6.4 (23.5; 10-33)
Chance Externality-MHLC[b]	18.2±6.2 (15; 6-30)	17.4±3.8 (18; 9-22)	12.7±9.9 (8; 6-24)	17.5±5.9 (18; 6-30)

[a] Multidimensional Health Locus of Control. [b] Mean + standard deviation (median; range). [c] All biological mothers of the children, except one grandmother and one foster mother. A boy and a girl in the Penicillin group had the same caregiver, their mother whose adherence scores for both the children was 8. Her Morisky and MHLC scores were counted only once in data analyses. [d] Eleven women and 2 men, all biological parents of the children, except for one grandmother and one elder brother. [e] Two mothers and a grandmother. [f] No significant difference in adherence between the penicillin and the hydroxyurea groups (t-0.27, df 37, p=0.79). No significant relationship between treatment adherence and sex of the child (t-0.14, df 41, p=0.97), or age of the child (r -0.1, p=0.54). [g] Thirteen (31%) caregivers scored in the low adherence range (<6) on MMAS-8, 11(26%) in the medium adherence range (6 or 7), and 18(43%) had a full adherence score of 8. [h] Difference between penicillin and hydroxyurea groups significant (t-2.09, df 37, p=0.043, 95% confidence interval of the difference -8.33, -0.14, equal variances assumed).

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