

Development and Evaluation of a Patient Empowerment Video to Promote Hydroxyurea Adoption in Sickle Cell Disease

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Background: For the last decade, compelling evidence on hydroxyurea (HU) efficacy in certain adult patients with sickle cell disease (SCD) has supported recommendations for use of this drug to decrease morbidity and medical costs. Despite these benefits, HU therapy is underused in patients meeting treatment criteria. The purpose of this study was to develop and evaluate an educational video to empower patients and their families to initiate a conversation with their physicians on the benefits and risks of HU, encouraging a shared decision-making process.

Methods: Patients with SCD and physicians with prominence in the sickle cell community were selected to participate in the video based on their communication skills. They were encouraged to answer interview questions on camera with language that could be easily understood by all patients. Two focus groups participated in the development process verifying the messages in the video were clear and easy to understand. A pre- and postdesign survey of patients was performed to assess patient acceptability and utility of the video.

Results: A 15-minute educational video was produced and modified from input of the focus groups. Impact of the refined educational video was evaluated with a patient survey. Patients expressed a strong desire after viewing the video to learn about potential benefits of HU. Furthermore, the video was useful in heightening the intent of patients to ask their health care providers about HU therapy.

Keywords: hydroxyurea ■ education ■ sickle cell anemia

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INTRODUCTION

More than 80 000 Americans suffer from sickle cell disease (SCD), a group of chronic genetic disorders affecting predominantly African Americans, where abnormal red blood cells undergo shape change when deoxygenated leading to vaso-occlusion and tissue ischemia.^{1,2} The clinical and economic burden of SCD is substantial.³⁻⁵ Symptoms manifest as chronic or episodic pain episodes; acute potentially life-threatening illness, such as acute chest syndrome or severe anemia; and organ failure, such as pulmonary hypertension, stroke, and renal failure.⁶⁻⁸ These manifestations negatively impact the patient's quality of life and lead to early mortality.⁹⁻¹¹ Management of patients with SCD includes blood transfusions and hospitalizations with certain patients requiring frequent visits to the emergency department and inpatient stays for vaso-occlusive episodes.¹²⁻¹⁴ Hydroxyurea (HU), an oral anti-neoplastic agent, is currently the only FDA-approved disease-modifying therapy for adults with sickle cell anemia.^{15,16} Compelling clinical evidence has supported the use of HU in SCD; however, HU is currently underused in the management of symptomatic patients.¹⁷⁻²⁰ Recommendations from a recent National Institutes of Health Development Consensus Conference on HU therapy for SCD include addressing barriers that have impeded the use of HU at the health systems, provider, and patient levels.²¹

Previous research in chronic disease management has identified patient education as an important strategy to increase patients' knowledge about their disease, to encourage patient-physician discussions about current treatments, and to empower patients to discuss treatment strategies with their physicians.²²⁻²⁶ Patients are said to be empowered when they are knowledgeable and confident enough to ask their physician questions in order to promote an open dialog about treatment options and health care decisions. In a health care system transitioning from physician-centered to patient-centered collaborative care, educational interventions help empower

patients to make informed decisions about their health and encourage patients' participation in their health care (self-efficacy). Some researchers suggest that increasing patients' participation in their health care experience improves quality of care and subsequent patient satisfaction with the medical care received.^{23,26,27} Therefore, it is conceivable that patient education could increase awareness and subsequent use of HU therapy. Potential patient barriers to increasing HU use include lack of patient knowledge concerning treatment, misperceptions about drug induced side effects and low health literacy.²⁸⁻³² Patients with a low education level may have difficulty evaluating the benefits and risks of treatment, asking questions about specific health concerns, and/or making informed decisions concerning their health. Research from the 1993 National Adult Literacy Survey shows that more than half of adult Americans have literacy skills that are at best limited, and that 70% of adults with long-term illnesses have literacy problems. In addition, racial and ethnic minorities are also more likely to have lower literacy levels.²⁸

One strategy to increase HU use involves facilitating patient-provider communication by empowering patients to discuss the benefits and risks of available treatment options with their physicians. Patients can receive health information from a variety of sources, including family and friends, medical Web sites, community or disease support networks, medical pamphlets, and educational videos. A patient educational video was considered to be a suitable vehicle for addressing HU therapy in SCD. Videos are convenient, portable, and time-efficient vehicles to convey medical information because they can be used to discuss and demonstrate messages to patients who may have low health literacy.³²⁻³⁵ An educational video on HU can be easily incorporated into a clinical or home setting, and could also trigger patient interest in HU or facilitate patient-physician interactions. Finally, it could assist patients and family members in consultation with physicians in making an informed decision concerning HU use. An educational video was developed to increase awareness about HU and empower both patients and family members to approach their physicians with inquiries about the suitability of HU in their disease state. A study was carried out to determine whether this approach was acceptable and useful in enhancing patients' intent to initiate patient-physician interaction pertaining to HU therapy.

METHODS

Video Development

A comprehensive review of available patient educational materials on HU therapy revealed that materials were often difficult to find, and those that were found either contained limited information directed to patients and families or were written using technical language. A

patient education and empowering video, including information about SCD, current treatment options, and questions to facilitate patient-provider interactions about HU, was developed by a multidisciplinary team. The team consisted of hematology/oncology physicians with SCD expertise, video production specialists in health science communication, Sickle Cell Disease Association of Florida (SCDA-F) community outreach coordinators, and patients with SCD.

In order to gain a better understanding of SCD and patient attitudes towards HU treatment, a video production specialist attended the Shands Hospital at the University of Florida hematology clinic to interview patients and health care professionals. Over the course of several months, more than 30 patients were interviewed about their health care experiences and understanding of HU therapy. Four participants were chosen to be interviewed an additional time for the production of the video in order to allow adequate time to relay their messages. Three participants were chosen because they were captivating, had positive experiences with HU, and wanted others to know about HU therapy.

Video content was developed based on gaps in patient knowledge discovered during patient interviews and observed by physicians caring for patients with SCD. The video was also developed using similar modeling, since research has shown that watching a model similar to oneself accomplish a difficult task is more convincing than observing someone of a different race or gender.³⁶ Since the US sickle cell population is predominantly African American, the patients and professionals chosen to take part in the video were African American.

Kenneth Ataga, MD, an expert in sickle cell patient care and HU therapy, was chosen to discuss the benefits and risks of treatment. Lanetta Jordan, MD, director of sickle cell services at a large community-based medical center, was chosen to address how patients can talk to their physicians about issues surrounding treatment.

The primary objective of the project was to develop a video that communicates messages that all patients and their families could relate to and understand. The individuals appearing in the video were encouraged to use language that was easy to understand. Sections of the interviews where patients answered questions about how a pain episode feels and the importance of family involvement were included in the video so that patients and families could relate to the subjects.

Patients, family members, and nurses from SCD clinics in Gainesville and Hollywood, Florida, were recruited for focus groups to assist in refining the video. These groups verified that the messages in the video were clear and easy to understand. Recommendations for including additional information (eg, emphasizing HU is an oral medication) were incorporated.

Hydroxyurea Pamphlet Development

A printed patient pamphlet, prepared at a sixth-grade reading level, was developed to accompany the patient education video. This 1-page, 3-fold pamphlet reinforces key points from the video and also provides a list of questions for patients to ask their physicians. Furthermore, the video and brochure both encourage SCD patients to watch the video with family members or close friends, and to bring the pamphlet to their next physician appointment.

Survey Design and Data Collection

This study used a pre-and postsurvey design method to evaluate whether the educational video had an effect on patients' understanding of and/or attitude toward HU therapy. Structured questionnaires were administered post intervention to assess patients' attitudes toward HU and intent to ask their health care providers about the appropriateness of HU as part of their treatment plans. Intent was assessed because the follow-up period was not sufficient enough to measure patient behavior. The postintervention questionnaire included additional questions to assess the patients' opinions of the video's presentation of content and format of the video. The questionnaires utilized both open- and closed-ended questions. Closed-ended questions employed a 7-point Likert scale (1 = strongly disagree to 7 = strongly agree). Each questionnaire was assigned a corresponding number to allow individual baseline and postintervention

responses to be compared and to ensure participants' anonymity and confidentiality.

Approval was obtained from the University of Florida's institutional review board and human subjects research review committees, and informed consent was obtained from individuals meeting the study inclusion criteria prior to data collection. The target population consisted of adults 18 years and older in Florida diagnosed with SCD. Individuals with sickle cell trait and patients participating in the focus groups were excluded from the study.

Community outreach coordinators from SCDA-F distributed the educational videos and surveys to adults with SCD during regularly scheduled SCD clinic or home visits. Prior to the study's implementation, the outreach coordinators received guidance from one of the research team members about the purpose of the study, content of the survey, and instructions on administering the surveys and recording the responses in a standardized manner. The outreach coordinators assisted patients in completing the pre- and post-video-viewing surveys by reading each question aloud and recording the responses. As an incentive to completing the study, respondents received a \$10 gift certificate. Descriptive analysis of the survey responses were performed using SAS 9.1 (SAS Institute, Cary, North Carolina) statistical software. Due to the sample size, Likert scores of 1 to 2 and 6 to 7 were summated into single scores yielding a 5-point scale.

Table 1. Summary of Educational Video Content

Patient	Physicians	Health Advocacy
1. Experiences with sickle cell painful episodes	1. HU mechanism of action.	1. Approach to initiate discussion about HU with health care providers
2. Impact of SCD on patients' quality of life	2. Patients considered candidates for HU therapy	2. Questions to ask health care provider about HU
3. Experience with HU and the effect of HU on reducing SCD complications	3. How a patient may qualify for HU	3. Importance of taking initiative
4. Approaches used to ask patients' physicians about HU and how treatment was initiated	4. Benefits of HU	
5. Suggestions for other SCD patients considering HU	5. Possible HU side effects	

Abbreviations: HU, hydroxyurea; SCD, sickle cell disease.

Table 2. Summary of Topics Included in the Pamphlet

Topics Addressed	Patient Questions for the Physician
<ul style="list-style-type: none"> • Benefits and side effects of HU • Asking a physicians about HU • The benefits of bringing a family member or friend to a scheduled physician visit 	<ul style="list-style-type: none"> • Is HU a good idea for your SCD condition? • Will HU interact with any other drugs? • How long will HU take to work? • How long will HU treatment last? • What are some HU side effects to expect? • What risks are associated with HU use during pregnancy and breastfeeding?

Abbreviations: HU, hydroxyurea; SCD, sickle cell disease.

RESULTS

Patient Educational Video

A 15-minute DVD entitled “Hydroxyurea: Is it Your Hope for Better Days?” included patients discussing experiences with HU, and SCD experts discussing risks and benefits of HU and potential questions for patients to ask physicians. A summary of the video’s content is categorized in Table 1. The video can be viewed at <http://pharm.digiscrypt.net/B33/550027/player.HTM#>. Table 2 summarizes the key topics and patient questions included in the pamphlet that accompanied the video.

Survey Analysis

A total of 58 pre- and post-video-viewing surveys were returned. Baseline information on SCD reported by study respondents is displayed in Table 3. Respondents reported having hemoglobin SS, SC, or S/β-thalassemia and represented 9 geographic regions in Florida (n = 2-10 from each region). Patients indicated experiencing SCD complications, such as acute chest syndrome (69%), and 55 respondents indicated the occurrence of at least 1 pain crisis requiring hospitalization in a 1-year period.

Table 4 summarizes pre-video-viewing intentions of participants concerning new therapies and familiarity with HU. The majority of respondents (66%) were cognizant of HU prior to participating in this study. A minority of respondents (20%, 9 of 46) indicated previously or currently taking hydroxyurea, whereas more than half (54%) indicated having a family member or acquaintance having taken HU.

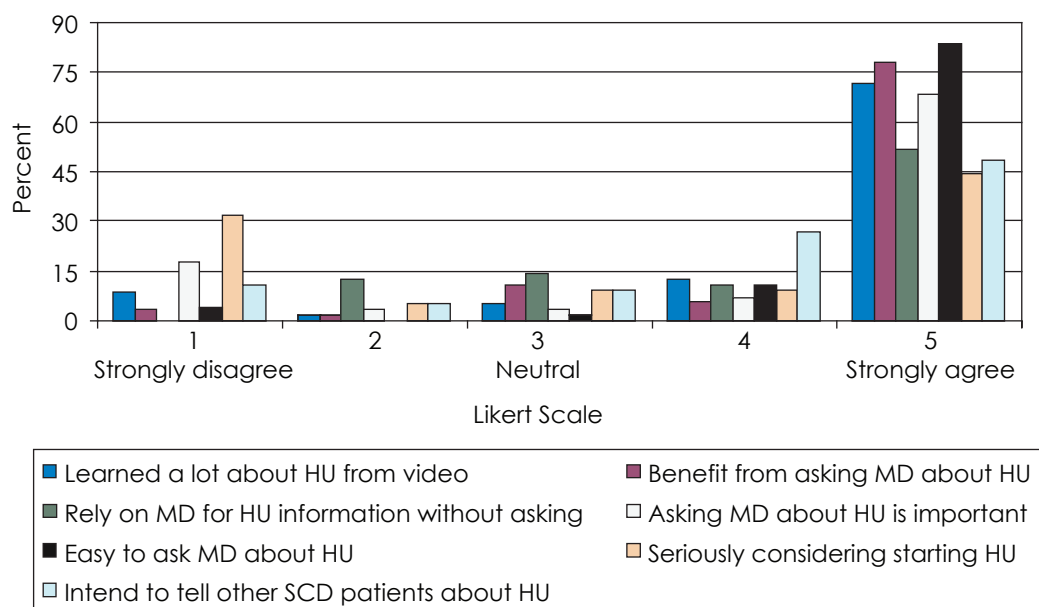
Patient perceptions of the utility of the video were

obtained from the post-video-viewing questionnaire. More than half (56%) of the respondents viewed the educational video alone, while others viewed it with a family member (44%). Almost all respondents viewed the complete video (95%). Most respondents watched the video once (66%), while some reported multiple viewings (34%). The majority of respondents indicated they were able to understand the video message (79%), and most viewers indicated that the video changed their feelings about HU in a positive way (78%); only 5% indicated a change in the negative direction.

Respondents appeared to find viewing the video was beneficial (Figure 1). After viewing the video, approximately three-quarters of the respondents (72%) gained new knowledge concerning the effectiveness of HU. In addition, respondents indicated that asking their physician about HU would be an easier task after viewing the video (84%), and that discussing HU as a part of their treatment plan is important (68%). Participants displayed a willingness to ask about new treatments, specifically HU, as supported by the pre- and post-video-viewing surveys, respectively. Forty-five percent of the respondents considered starting HU therapy after viewing the video.

The education/empowerment video appeared to trigger patient interest in discussing HU therapy with physicians. A few participants had taken educational pamphlets to their physician visits (13%) (Table 5) or intended to do so within 1 month (47%). Moreover, approximately half of the respondents (49%) reported their intention to inform other patients with SCD about HU. Despite recommendations made in the video to allow either a family member or acquaintance to accom-

Figure 1. Post-Video-Viewing Responses by Frequency of Respondent Attitudes Toward Hydroxyurea Therapy



pany them, more than half of the respondents (56%) preferred to go to their physician appointments alone. This intent remained unchanged after viewing the educational video.

Respondents indicated a number of reasons for asking their physicians if HU was appropriate for them, including: (1) desire for relief from pain crises, (2) promising medication outcomes, or (3) desire to explore additional treatment options. Conversely, negative past experiences with new treatments, low disease severity, treatment contraindications (breastfeeding), negative side effects of HU (ie, lowering the number of white blood cells and platelets in blood), and contentment with current treatment were among the reasons given for respondents' reluctance to approach their physicians about HU after watching the video.

Respondents with a previous history of HU use described positive experiences such as reduced pain episodes and hospital admissions, increased hemoglobin and improved overall health state. Moreover, negative experiences with previous HU use included adverse side effects (eg, hair loss), no improvement in health outcomes, longer pain crises, and a drop in blood counts.

DISCUSSION

This educational video was developed to engage and educate patients about the potential benefits of HU therapy. The messages in the video support HU as a major advance in the management of SCD and emphasize consideration as an important treatment option.²¹ The video was developed to serve a unique purpose in dealing with a treatment modality that is complicated, as it has the ability to inform patients and/or family members who may have literacy problems.

The patient survey evaluated whether audio-visual media increased patients' knowledge about HU while empowering them to discuss the benefits and risks of HU therapy with their physicians. Previous studies have suggested that increased access to online, written, or televised educational sources empowers patients to become more educated about their disease state.²²⁻²⁷ Ideally, educational materials should encourage patients to make informed decisions about their disease, while facilitating increased physician-patient interactions in regards to current treatment options. Our results suggest that the HU patient education/empowerment video and pamphlet were useful in assisting patients and their families in understanding the issues surrounding HU and in enabling patients to potentially engage their physicians in a discussion about HU therapy. Respondents indicated that the video provided useful information and encouragement to ask their physicians about HU therapy.

Previous research has shown that educational/empowerment tools raise awareness of therapy options and have important implications for overcoming communication barriers that SCD patients encounter. Traditional reliance on written health-related educational materials to communicate with patients has met with limited success due to low literacy, particularly among the elderly, and racial and ethnic minorities.^{28,29} Utilizing an educational video instead of written literature can reduce the literacy barrier, increase access to health information, and stimulate increased patient interest. Also, use of educational/empowerment tools such as the HU video would be useful for patients transitioning from provider-centered care to patient-centered collaborative care.²⁴

Our evaluation study has limitations. A convenience sample of Florida SCD patients was recruited by com-

Table 3. Characteristics of Survey Respondents (n = 58)

Variables	Number of Respondents	
	n	(%) ^a
Type of sickle cell disease		
Hemoglobin SS	32	(57.1)
Hemoglobin SC	13	(23.2)
Hemoglobin S/β-thalassemia	7	(12.5)
Unknown	4	(7.1)
SCD complications		
Acute chest syndrome		
Yes	36	(69.2)
No	16	(30.7)
Number of pain crises requiring hospitalization in 1 year		
1	12	(21.8)
2	9	(16.4)
≥3	34	(61.8)
Frequency of sickle cell pain		
Every day	3	(5.4)
Few times a week	10	(17.9)
Few times a month	20	(35.7)
Every few months	23	(41.1)

^a Difference in n due to missing data.

munity outreach coordinators. Certain demographic characteristics of respondents were not recorded due to the study design to assure no identifying information was collected. However, the participants were representative of adults with SCD in contact with outreach coordinators residing in 9 distinct geographic regions of Florida capturing both urban and rural populations. Further research using a larger patient population with SCD and obtaining demographics of respondents would provide stronger results. Every effort was made to avoid ambiguity by using primarily closed-ended questions. Using an audio-visual medium was found to be an effective way to empower SCD patients to ask their health care providers about proven treatment options and to make informed decisions as part of a shared decision-making process. Future research will focus on pursuing a wider distribution of the patient education/empowerment video and pamphlets through national and regional advocacy groups, with the expectation of increasing patient aware-

ness of HU and empowering patients to discuss HU with their physicians. This approach as part of a multifaceted program is important because the adoption of HU in the treatment of SCD has been suboptimal.

Using audio-visual materials addressing HU therapy may be an effective way to communicate with patients faced with the complexities of this particular treatment. The results indicated that after watching the educational video, patients expressed a strong desire to learn more about how hydroxyurea could offer relief for SCD complications and the intent to ask their health care providers about hydroxyurea.

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Table 4. Pre-Video-Viewing Responses (n = 58)

Survey Question	No. of Respondents, n (%) ^a
It would be easy for you to ask your doctor about a new treatment option.	
1 = Strongly disagree	1 (1.7)
2	0 (0)
3	2 (3.4)
4	10 (17.2)
5 = Strongly agree	45 (77.6)
Do you intend to ask your doctor if a new treatment option is right for you?	
Do not	9 (16.1)
Already have	21 (37.5)
Will within 1 month	26 (46.4)
Do you intend on bringing a family member or friend with you when asking your doctor about a new treatment option?	
Do not	30 (52.6)
Already have	16 (28.1)
Will within 1 month	11 (19.3)
Have you heard of hydroxyurea before?	
Yes	38 (65.5)
No	20 (34.5)
Do you know of anyone who has taken or who is currently taking hydroxyurea? (Please check all that apply.)	
Myself	9 (19.6)
Family	9 (19.6)
Friend/acquaintance	16 (34.8)
None	12 (26.1)

^a Difference in n due to missing data.

Table 5. Summary of Respondents' Intentions Regarding Hydroxyurea Therapy (n = 58)^a

Items	Action Already Taken	Intent Within 1 Month	Do Not Intend
	n (%)	n (%)	n (%)
Intention to ask physician if HU is right for them	22 (38.6%)	26 (45.6%)	9 (15.8%)
Intention to take HU pamphlet to physician visit	7 (12.7%)	26 (47.3%)	22 (38.6%)
Intention to bring family member or friend when asking about HU	18 (31.6%)	7 (12.3%)	32 (56.1%)

Abbreviation: HU, hydroxyurea.

^a Difference in n due to missing data.

team from University of Florida College of Journalism and Communications provided audio-visual development and technical assistance. The Sickle Cell Disease Association—Florida community outreach coordinators partnership facilitated the distribution of the educational video and collection of survey data.

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