Tailoring a Social Needs Assessment Tool for an Urban Latino Population

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Abstract

Introduction: Patient Reported Outcome (PRO) measures are methods for patients to report on their health-related quality of life. The purpose of this study is to adapt a social needs assessment tool, Beacon Patient Reported Outcome Quality of Life (PROQOL), to identify and address unfulfilled social needs in the Lehigh Valley Health Network (LVHN) patient population. Approximately 40% of health outcomes are due to unmet social needs, therefore the identification of such needs by Beacon PROQOL can enable providers to better meet both the social and medical demands of their patients.

Specific Aims: This study aims to develop a list of priority social need domains and to generate a collection of appropriate images to represent the identified social need domains. This information will be used to adapt or create a new social needs assessment tool tailored to the unique social needs of the LVHN patient population.

Methods: In Phase 1, four focus groups of 42 participants were conducted in order to assess social needs and current utilization of community resources in the LVHN population. In Phase 2, 18 focus groups divided by ethnicity, preferred language, and age will be administered in order to assess patient impression of the text and icons of the Beacon PROQOL tool and to compile a list of priority social need domains with corresponding icons.

Results: Phase 1 identified a diverse group of unmet social needs including transportation, food and nutrition, affording medications, access to health insurance, opportunities for recreation, financial support, access to healthcare, and access to mental health and addiction services. After identifying the barriers that seem to be limiting patient ability to maintain health, participants identified existing resources, gaps/barriers within resources, and ideas/opportunities that may serve as potential modes to surmount the named social barriers. The barriers with fewer corresponding resources may represent priority social areas with greatest need.

Discussion: In 4 focus groups of 42 participants in Phase 1, there were a diverse group of unmet social needs identified in the community. While the groups were able to articulate more resources for some barriers than others, there are still many resources not named by participants. This indicates that a comprehensive and accessible database of resources per geographic area, such as the one currently used by the Children’s Hospital of Philadelphia, would better enable patients to locate the necessary resources to surmount barriers that limit their access to health care. Now that we have an understanding of some of the areas of need, we will do a more in depth evaluation of the specific priority areas during Phase 2. The ultimate goal is to use all of this exploratory information to adapt or develop a new tool to be systematically incorporated into an adaptation of the Health Leads (HL) model developed by the Boston Medical Center. Further study will assess how many social needs, once identified, were addressed, as well as the impact of this intervention on overall health, quality of life, and cost of care.
Keywords

Health information technology, social needs, patient-reported outcomes, health disparities

Introduction

Patient Reported Outcome (PRO) measures are methods for patients to report on their health-related quality of life. These tools serve to improve the quality of healthcare by allowing providers to respond to patient identified needs. With the shift to patient-centered approaches in health care represented by the Patient Centered Outcomes Research Institute (PCORI) and the ease of access to technological tools (such as iPads, web-based tools, and kiosks), PRO measure implementation is more feasible than ever before.

The purpose of this study is to adapt a social needs assessment tool, Beacon Patient Reported Outcome Quality of Life (PROQOL), to discern unfulfilled social needs in the Lehigh Valley Health Network (LVHN) patient population. Beacon PROQOL (see Figure 1 in appendix) is a computerized interactive survey tool, previously developed by the Mayo Clinic, which serves to collect PRO data in 9 priority areas. Originally, Beacon PROQOL was designed for patients with diabetes; thus, a goal of this study is to expand the use of the tool to effectively assess a wide range of social needs across a diverse patient population. According to Marshall et al. (2006), a multi-dimensional PRO tool, such as the one being developed by the expansion of Beacon PROQOL, is necessary for the desired shift to patient-centered care.

Approximately 40% of health outcomes are due to unmet social needs, therefore the identification of such needs by Beacon PROQOL can enable providers to better meet both the social and medical demands of their patients. The desired outcomes of this project are to develop a list of the critical social needs of our community and to determine relevant images to represent the social needs identified. This data can then be utilized in order to adapt Beacon PROQOL to the social needs of our community. Furthermore, this will allow for the generation of social prescriptions in order to compile a list of potential resources to address the identified unmet need that is unique to the Lehigh Valley.

Ideally, adaptation of Beacon PROQOL to identify the social needs of the LVHN patient population will lead to the development of a model that resembles the Health Leads (HL) model established by the Boston Medical Center in 1996. The HL model serves to address patients’ unmet social needs by a systematic approach. In this model, the patient completes a pre-visit screening survey to assess their unique social needs; based on needs revealed by this survey, the patient is referred to HL where undergraduate volunteers then work to connect patients with community-based resources in an effort to improve patient outcomes. In order to eventually replicate this model, it is the goal of this study to adapt Beacon PROQOL to accurately identify the social needs unique to the LVHN patient population for use as the pre-visit screening survey mentioned in the HL model.

Specific Aims

As shown in Table 1 (see appendix), the three main goals of this study are to determine the priority social need domains, to identify images to represent these social
need domains, and to use this data to adapt Beacon PROQOL to address the unique needs of the LVHN patient population.

Methods

After IRB approval, the scope of the social needs of the LVHN patient population was evaluated by the administration of four focus groups of 42 participants during Phase 1 of this study (see Figure 2 in appendix). Two of these groups were conducted in English, while the other two groups were held in Spanish. The ethnicities, ages, and genders of the groups were mixed; however, patients below age 18 were excluded from the study. Focus groups were recorded and transcribed. After obtaining informed consent, patient demographic information and patient perception of priority social needs in the community were acquired. Qualitative analysis was performed to identify key themes for the responses on experiences with and preferences for community resources. Responses were grouped according to the corresponding existing resources, gaps/barriers, and ideas/opportunities for each social need identified (i.e. transportation, access to nutritious food, etc.).

The purpose of Phase 2 of this study is to qualitatively assess patient perception of Beacon PROQOL as a tool to identify the priority social needs of patients in our unique community and to obtain patient opinions on the most recognizable icons to represent these social need domains. Identifying appropriate images with the social need domains will be critical for those with low literacy. These goals will be accomplished through the administration of eighteen focus groups, described in Table 2. As shown, focus groups will be divided by ethnicity, preferred language, and age. There will be six Hispanic – English speaking focus groups, six Hispanic – Spanish speaking focus groups, and six Non-Hispanic – English speaking focus groups. Each category of focus groups, just described, will have two groups in each of the following age categories: 18-34, 35-64, 65 and over.

The reason for the division of groups by age is the thought that older patients will be less comfortable with use of iPads than younger individuals. In addition, the priority social needs of patients may differ with age; older patients are more likely to be plagued with chronic illnesses, while younger patients may have concerns related to the workforce or their families.

After attainment of informed consent, focus group participants will be given iPads prepared with the Beacon PROQOL tool. After being given time to explore the program, they will be asked questions to evaluate their impressions of the texts and graphics of the tool. Focus group participants will also be shown a packet of images that correspond to social need domains in order to evaluate which icons are most representative for each domain, in addition to the icons currently being used within the PROQOL tool. Furthermore, they will be asked to rank their top three priority social need domains and preferences for icons. Focus group participants will be remunerated with a $25 Wawa gift card. Mixed methods data from these focus groups will be analyzed with descriptive statistics for the ranked social need areas and icons and with qualitative analysis for the contextual themes. Data obtained from these focus groups will be analyzed qualitatively to compile a final list of social need domains and corresponding icons. Phase 2 of this study is currently in the patient enrollment stage, with focus groups anticipated to begin in early August.
Results

The results of Phase 1 can be represented as a list of priority social barriers for which there is a need in our community, as well as existing community resources that are available to assist patients in overcoming these barriers. The priority social need areas identified by 42 participants in 4 focus groups were transportation, food and nutrition,affording medications, access to health insurance, opportunities for recreation, financial support, access to healthcare, and access to mental health and addiction services. After identifying the barriers that seem to be limiting patient ability to maintain health, participants identified existing resources within the community that may serve as potential modes to surmount the gaps and barriers that they identified. Additionally, participants generated new ideas and opportunities that may serve to bridge the gaps they identified. In Figure 3 (see appendix), the identified barriers and their corresponding resources are shown. The barriers with fewer corresponding resources may represent priority social areas with greatest need.

As evident in Figure 3 (see appendix), three of the main priority social need areas identified were financial support, affording medications, and health insurance. These barriers are identified as priority areas because they have fewer corresponding resources that allow community members to overcome these gaps. For example, only three resources were listed to aid patients in gaining financial support, they are: LVHN Reduced Cost Care (RCC) Plan, Financial Assistance Program (welfare), and shelters. However, even these resources did not entirely seem to address the problem of financial support as many patients expressed the sentiment that they are “not poor enough, but…not able to afford it.” Focus group participants thought that the establishment of a resource to instruct people on how to budget their money or the sharing of time frames of re-certifications for welfare and RCC might be alternative methods to surmount the barrier of financial support.

Poor access to medications was another barrier identified for which participants could only report five existing community resources: lower cost prescriptions at Walmart, Giant, and Wegmans, home delivery services/90 day prescriptions, free samples, discount cards, and the Lehigh Drug Store (One Pharmacy). Several patients explained that purchasing their medication often requires a sacrifice of other necessities, such as food. This often results in what physicians perceive as patient non-compliance to their medication schedule. As one patient explained: “Instead of it [medication] lasting thirty days, I’d try to make it last sixty so that I can afford my medication.” Focus group participants believed that incorporation of prescription coverage into LVHN’s RCC program would improve the ability of many patients to afford their medications.

Finally, a lack of health insurance was also identified as a barrier to access to healthcare in the LVHN patient population. Resources identified by focus group participants were government health plans, services to provide assistance in selecting an insurance product, Medicare, APPRISE volunteers, AARP, and Main Street Financial Partners. Despite these available resources, the focus groups still revealed an uninsured population without access to care. For example, as one participant shared: “It’s been ten years since he’s been to a doctor for a check up. Look how old he is, and that is all due to the lack of resources.” The focus group participants
expressed no ideas on how their access to health insurance could be improved.

**Discussion**

The purpose of this research project is to adapt Beacon PROQOL, a social needs assessment tool, to the unique social needs of the LVHN patient population. In four focus groups of 42 participants there were a diverse group of unmet social needs identified in the community. A list of eight priority social needs was compiled from the Phase 1 focus groups. Of the identified barriers, financial support, affording medications, and access to health insurance were identified as potentially having the greatest need due to the deficiency of existing community resources that serve to relieve obstacles created by such barriers.

While the groups were able to articulate more resources for some barriers than others, there were still several gaps in needed resources, as well as ideas for future opportunities to better serve the community. For this reason, the gaps in resources revealed by this data can be used to develop and expand on the resources available to help patients overcome the identified barriers. However, it is important to note that there are many more resources available that were not named by participants. This indicates that a comprehensive and accessible database of resources per geographic area, such as the one currently used by the Children’s Hospital of Philadelphia, would better enable patients to locate the necessary resources to surmount barriers that limit their access to health care.\(^\text{vii}\)

Overall, the preliminary feedback gathered from the first set of focus groups identified social needs in the community, including some of the needs that are presently listed on the PROQOL tool. Now that we have a better understanding of some of the areas for need in our patient population, we will do a more in depth evaluation of the specific priority areas in subsequent phases of the study. The goal of Phase 2 is to affirm the social need areas identified in the Phase 1 focus groups across diverse age groups and ethnicities to ensure a comprehensive list of high priority social needs. Additionally, Phase 2 aims to assess patient preferences for the text and graphics of Beacon PROQOL in order to effectively remodel the tool. In recognition of low literacy and low health literacy in this population, images that correspond to the needs will be evaluated to see which are most recognizable in our community.

A challenge to data collection that may propagate through Phases 1 and 2 of this study is determent from the primary research question within focus groups. That is, due to the utilization of focus groups to assess patient priority social need areas, a potential challenge to data accumulation is the difficulty of maintaining participant focus on the primary research topic.\(^\text{vii}\) This challenge may limit the amount of valuable data obtained from the focus groups.

The ultimate goal is to use all of this exploratory information to allow for the adaptation or development of a social needs assessment tool (during Phase 3) to be systematically incorporated at the point of care in order to identify and address unmet social needs by connecting each unmet social need to a list of possible resources. Therefore, the implementation of Phase 4 will result in a replication of the HL model. Further study will assess how many social needs, once identified, were addressed, as well as the impact of this intervention on overall health, quality of life, and cost of care.
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Appendix:

Figures:

![Figure 1: The Beacon Patient Reported Outcome Quality of Life (PROQOL) interface.](image1)

![Figure 2: Proposed plan for ongoing study utilizing local medical and community resources.](image2)
Phase 1 Results

Figure 3: The barriers and number of corresponding community resources identified in Phase 1 focus groups.

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Table 1: The specific aims and outcomes of the study.

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Table 2: Composition of Phase 2 focus groups.
References:


