

Research Article

Partnering with patients using social media to develop a hypertension management instrument



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Abstract

Hypertension is a lifelong condition; thus, long-term adherence to lifestyle modification, self-monitoring, and medication regimens remains a challenge for patients. The aim of this study was to develop a patient-reported hypertension instrument that measured attitudes, lifestyle behaviors, adherence, and barriers to hypertension management using patient-reported outcome data. The study was conducted using the Open Research Exchange software platform created by PatientsLikeMe. A total of 360 participants completed the psychometric phase of the study; incomplete responses were obtained from 147 patients, and 150 patients opted out. Principal component analysis with orthogonal (varimax) rotation was executed on a data set with all completed responses ($N = 249$) and applied to 43 items. Based on the review of the factor solution, eigenvalues, and item loadings, 16 items were eliminated and model with 29 items was tested. The process was repeated two more times until final model with 14 items was established. In interpreting the rotated factor pattern, an item was said to load on any given component if the factor loading was ≥ 0.40 for that component and was < 0.40 for the other. In addition to the newly generated instrument, demographic and self-reported clinical characteristics of the study participants such as the type of prescribed hypertension medications, frequency of blood pressure monitoring, and comorbid conditions were examined. The Open Research Exchange platform allowed for ongoing input from patients through each stage of the 14-item instrument development. *J Am Soc Hypertens* 2015;9(9):725–734. © 2015 The Authors. Published by Elsevier Inc. on behalf of American Society of Hypertension. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Keywords: Assessment tool; blood pressure; patient-reported outcomes; social networking.

Introduction

It is estimated in the United States that 75% of individuals with uncontrolled hypertension visited a health care provider at least twice in the prior year.¹ However, because hypertension is a lifelong condition, long-term adherence to lifestyle modification, self-monitoring, and medication

regimens remains a challenge for patients. Only half of Americans with hypertension have a blood pressure $< 140/90$ mm Hg.²

An increased global focus has been placed on developing strategies that improve adherence to treatment regimens and result in improved blood pressure control with the goal of improving health outcomes for patients with high blood pressure.³ The Centers for Disease Control and Prevention report that an estimated 16 million Americans know they have hypertension and are taking medication for it but do not have the condition under control. Research has evidenced that approximately 25% of all prescribed doses of medications are omitted by patients, whereas 30%–55% of patients with hypertension do not adhere to their prescribed medication regimen.^{3,4} Numerous physician-related barriers to the effective management of uncontrolled hypertension have been reported, and

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researchers found that physicians were not aggressive in the management of hypertension and patients with hypertension had inadequate control of their blood pressure.⁵

Carrington et al⁶ investigated hypertension management in 532,050 patients from 2005 to 2010 and found that 50% of the patients prescribed antihypertensive drugs had a blood pressure >140/90. Although researchers for decades have concluded that a more intensive approach to blood pressure management in primary care is required neither successful interventions nor instruments to measure hypertension management outcomes were developed to date.^{3,5,7–9} The lack of active patient involvement in hypertension research could have impeded scientific progress in this field. However, it appears a new trend is emerging, and the importance of including patients in the research process has been increasingly recognized over the past few years. As a result, patients are becoming increasingly engaged in research, whether as citizen scientists, research partners, or as engaged participants in clinical trials and reporting outcomes of conditions and disease processes.¹⁰

Patient-Reported Outcomes

A patient-reported outcome (PRO) is best defined as any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the response by a clinician or anyone else.¹¹ Use of the PRO philosophy supports the importance of patient involvement and participation in blood pressure management and control. It is hypothesized that with health care providers' use of PRO instruments that identify attitudes, lifestyle and adherence practices, and barriers to effective hypertension management, patients will be empowered to gain personal control of high blood pressure in collaboration with the health care provider (physician and nurse). This approach to research and instrument development places the patient at the center of the process and incorporates patient input at each step of the process. This is empowering for the patient and provides needed information to the researcher and practitioner striving to understand a patient's experience living with a chronic illness.

In addition, there has been a rapid increase in the use of social networking sites for sharing a variety of health experiences such as diagnoses, treatments, and methods for coping with illnesses.¹² In a 2014 study conducted by PatientsLikeMe (PLM), 92% of the online users agreed to share their health data with researchers and 78% agreed to allow drug companies access to the same information.

In 2013, the Institute of Medicine's Roundtable on Value & Science-Driven Health Care convened a workshop, gathering patients and experts in areas such as decision science, communication strategies, and evidence generation to consider the roles for patients in bringing about progress in all aspects of the US health care system.¹³ Discussions at this roundtable meeting emphasized the essential role

and capacity for patients and families to be leaders in informed care decisions knowledge generation and value improvement.

Purpose

The aim of this study was to develop a patient-reported hypertension instrument that measures attitudes, lifestyle behaviors, adherence, and barriers to hypertension management using PRO data that incorporate patients' experiences and feedback. This hypertension management instrument known as the Kear Hypertension Management Instrument was developed using an Open Research Exchange (ORE) platform on the PLM social media health education site.^{14,15} The PLM online data platform (www.patientslikeme.com) was designed to allow patients with illnesses to share data about their experiences of symptoms and disability through structured data collection processes.¹⁶

Methods

The development of the Kear Hypertension Management Instrument was based on a series of steps recommended in the literature.^{11,17} The initial phase of the instrument development was based on a literature review of the already existing relevant measures to examine unmet needs among the available instruments, evidence in the literature on barriers to hypertension management, the clinical experience by one of the researchers, and input from patients and practitioners. A study conducted by the National Heart, Lung, and Blood Institute assessed barriers to effective blood pressure control (2004). The most frequently cited impediments to blood pressure control were lifestyle changes (67%), failure to take medications as instructed (42%), patients' lack of understanding of the problem (39%), physician fees (23%), cost of drugs (39%), and drug adverse effects (34%). A review of the literature revealed several instruments that measured the quality of life and symptoms experienced by patients with hypertension.^{6,18–20} In addition, several chronic illness instruments that could be useful with the patient population with hypertension were identified.^{4,21} It was evident that there was a lack of comprehensive measures specifically designed to measure attitudes, perceptions, adherence, and barriers to hypertension management and control. Most instruments measured a single factor such as medication adherence or health behaviors.^{18,22–27} Based on this literature review, it was determined that barriers to effective blood pressure management are multifactorial, yet a single instrument to measure these multiple factors was not located.

The first version of Kear Hypertension Management Instrument included blood pressure-specific items falling into four domains: (1) high blood pressure management and barriers to effective management, (2) adherence to high blood pressure treatment regimens, (3) attitudes about

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