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### Self-care difficulties and reliance on support among vulnerable middle-aged and older adults with chronic conditions: A cross-sectional study



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#### ABSTRACT

Objectives: Chronic conditions are pervasive among middle-aged and older adults. This study identified: (1) factors associated with participants reporting difficulties self-managing their chronic condition(s); and (2) factors associated with participants' reliance on external sources for ongoing help and support to improve their health and manage their health conditions.

Study design: Cross-sectional data were collected using the National Council on Aging Chronic Care Survey, a nationally representative telephone survey of adults aged 45 years and older with at least one chronic condition. *Main outcome measures*: Self-care difficulties among middle-aged and older adults with one or more chronic conditions and factors associated with reliance on ongoing help and support were examined.

Results: Among 731 middle-aged and older adults with one or more chronic conditions, 31% of participants reported their health condition(s) made it difficult for them to care for themselves. Participants who were Hispanic (OR = 3.08, P = 0.009), had three or more chronic conditions (OR = 3.05, P < 0.001), took more medications daily (OR = 1.07, P = 0.046), and experienced certain healthcare-related frustrations (P  $\leq$  0.023) were more likely to report difficulties self-managing their chronic condition(s). Participants relied on healthcare providers (40%), friends/relatives (20%), internet (9%), people with similar problems (6%), and community groups (3%) for help and support. Reliance on sources of support varied with participants' sociodemographic factors as well as healthcare and medication use.

Conclusions: Simultaneously considering patients' disease profiles, patient characteristics, difficulties managing their chronic conditions at home, and interactions with the healthcare system can inform tailored approaches and strategies to enhance patient education and resource identification, and can support service linkages.

#### 1. Introduction

Almost half of the U.S. adult population, or approximately 117 million individuals, have one chronic condition (e.g., heart disease, diabetes, cancer) [1] and half of those live with co-occurring chronic conditions [2]. The burden of chronic conditions increases with age [2] and also varies by race/ethnicity [3]. For example, older non-Hispanic Blacks and Hispanics report higher levels of diabetes (32% versus 18%) compared to non-Hispanic Whites [3]. In addition, the population of older adults is growing, with those aged 65 and older expected to double over the next 50 years [4]. Thus, identifying ways to ameliorate

disease and complications associated with disease among this rapidly aging population is timely.

Self-care, which refers to one's ability to "promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a healthcare provider", [5, p.17] is essential for the management of chronic diseases [6]. There is a growing body of literature documenting the impact that patients' chronic illness management has on their disease outcomes [7].

Unfortunately, individuals may face several barriers in successfully managing their chronic conditions. A qualitative study about barriers to self-care found that experiencing a lack of knowledge about chronic

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conditions, having financial constraints, and having limited social and emotional support were substantial barriers to self-care among adults living with multiple chronic conditions [8]. To counteract these self-care barriers, individuals living with chronic diseases may rely on others for help. Physicians and nurses may help provide self-management education to patients [9], yet disparities have been measured across racial and socioeconomic characteristics in having a usual source of care [10]. While health care professionals reflect more traditional medical treatment, informal care and support are also important factors in health care [11].

Family members and friends may provide instrumental support (e.g., helping with medications), emotional support (e.g., encouraging a healthy diet), and informational support (e.g., sharing illness-related information) [12]. In addition, peers living with similar illnesses have knowledge about the condition and may also offer information about how they are able to effectively manage their own illness [13].

However, to our knowledge, limited quantitative research has examined reliance on others for self-care among individuals living with chronic conditions. Thus, the purpose of the current study was to address this gap in the literature and obtain a greater understanding of self-care difficulties and sources of support reliance among middle-aged and older adults with one or more chronic conditions. Specifically, this study identifies: (1) factors associated with participants reporting difficulties self-managing their chronic condition(s); and (2) factors associated with participants' reliance on external sources for ongoing help and support to improve their health and manage their health conditions.

#### 2. Materials and methods

#### 2.1. Study participants and procedures

The National Council on Aging (NCOA) conducted a survey to better understand the lives of adults with one or more chronic conditions living in the U.S., including their experiences with the self-care of their chronic condition(s) [14]. The NCOA Chronic Care Survey is a nationally representative survey of adults aged 44 years and older with at least one chronic condition. Telephone-based interviewing was used as the data collection method through random digit dialing (RDD) sampling of landline telephone numbers. While recruiting from landlines only is no longer the preferred telephone-based sampling methodology to conduct nationally representative surveys (i.e., considering that, in 2014, 43% of the population only had cellphones [14]), oversampling was used to ensure an adequate representation in the sample. [15-17] Participants who reported having at least one chronic condition were included in the survey [18]. Informed consent was obtained verbally via telephone prior to data collection. Participation in this study was voluntary, and participants could withdraw from the study at any time. Details about the survey methodology, data weighting, and associated instrument used are described elsewhere [15-17].

As indicated in Fig. 1, a total of 1109 individuals were contacted for this study and 149 individuals refused to participate or reported no chronic conditions, for a total sample of 960 participants. Of the 960 adults age 44 years and older in the sample, 229 were omitted for incomplete data on variables of interest. Cases were omitted for missing data on difficulties managing chronic conditions (n = 15), external sources of reliance (n = 72), age (n = 40), race/ethnicity (n = 20), education (n = 20), marital status (n = 20), self-reported chronic conditions (n = 66), physicians asking about self-management at home (n = 34), and frustrations (n = 41). Some participants had missing data on more than one variables of interest. The final analytic sample contained 731 middle-aged and older adults with 1 or more chronic conditions. When comparing participants in the study (n = 731) to those omitted for missing data (n = 229), a significantly larger proportion of participants omitted from the study were female. No other significant differences were observed.

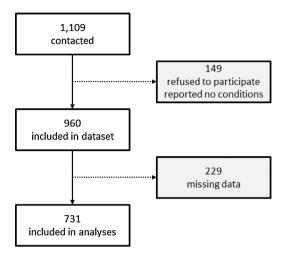


Fig. 1. Flow diagram for data analyses.

#### 2.2. Data and measures

#### 2.2.1. Dependent variables

Two dependent variables were of interest: difficulties self-managing their chronic conditions and external sources of reliance

#### 2.2.2. Difficulty in self-care

For the first variable, participants were asked to rate their level of agreement to the following statement: "All of my different health problems and conditions make it difficult for me to take better care of myself." Responses were scored on a 4-point Likert-type scale ranging from "strongly disagree" to "strongly agree." For analytical purposes, participants' responses were dichotomized into two categories: "disagree" and "agree."

#### 2.2.3. Reliance for help or support

Participants were also asked to rate their frequency of reliance on five different resources for ongoing help or support. Specifically, participants were asked: "How much do you rely on the following for ongoing help and support with improving your health and managing your health problems? Your friends or relatives; people who have similar health problems as you; your doctors, nurses, or other healthcare providers; community groups or clubs you belong to; and the internet." For each source, responses were scored on a 4-point Likert-type scale ranging from "a lot" to "not at all."

#### 2.2.4. Healthcare frustrations

Participants were asked to report their frustration with healthcare interactions from different perspectives. Participants were asked the following statements: "How often do you feel you leave the hospital or a doctor's office and feel confused about what you should do?" "How often do you feel you wish your doctor had more time to spend talking with you?" and "How often do you feel that your doctor does not realize what it is really like for you at home trying to take care of your health problems?" Responses were scored on a 3-point Likert-type scale with categories of "never", "occasionally" and "frequently."

#### 2.2.5. Perceived physician support

Participants were asked to rate the degree to which their healthcare providers offer details about medication, understand patients' situation at home, and contact patients for follow-ups. Participants were asked the following statements: "How often does your healthcare providers make plans to contact you after a visit to see how you are doing?" and "How often does your healthcare providers ask if you understand your medications when your doctor prescribes them, such as how and when to take them, possible side effects, and drug interaction?" Responses

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