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## Feature Article

## Measuring caregiver activation for health care: Validation of PBH-LCI:D

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## ABSTRACT

Improving the quality of health care for individuals living with dementia is a central goal of the National Alzheimer's Plan, and requires the participation of informed family caregivers as active members of the patient's health care team. "Caregiver activation" is an emerging concept for which dementia-specific measures are lacking. We developed and validated a new self-report index of caregiver activation, Partnering for Better Health – Living with Chronic Illness: Dementia (PBH-LCI:D). PBH-LCI:D has high content validity and good internal consistency and test-retest reliability, with 32 items and a strong six-factor structure reflecting all major health care domains of dementia caregiving. Comparisons with measures of related constructs and potential caregiver and patient predictors of activation indicate that PBH-LCI:D measures a unique construct and therefore should be useful as a marker of caregiver needs for education and behavioral change coaching, and as the foundation for developing interventions to enhance caregiver activation and successful partnership with clinicians.

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Mitigating the well-documented personal and societal burdens of dementia is the central focus of the National Alzheimer's Plan, which calls for extensive reforms in the delivery of health care for affected patients and support for the family and friends who care for them, collectively termed 'caregivers.'<sup>1</sup> In 2013 in the US, 15 million caregivers provided over 17 billion unpaid care hours<sup>2</sup> for people with dementia, whose progressive brain failure gradually undermines their autonomy and ability to understand and meet personal health care needs.<sup>3</sup> For the majority still living at home, most daily personal and health-related management (e.g. medication administration, monitoring signs and symptoms of illness, tracking management of comorbid conditions and safety risks) is provided by family members or friends,<sup>4</sup> who are usually unpaid and largely untrained for the many responsibilities they will take on over time.<sup>4</sup> Caregivers commonly perform skilled health care tasks at home, often with little or no oversight by clinicians.<sup>5</sup>

Dementia is now approaching epidemic prevalence, with economic costs matching or exceeding those of other major chronic diseases.<sup>6</sup> These high costs are mainly related to acute medical care,

some of which is preventable,<sup>7</sup> and long-term institutional care, which becomes necessary when caregivers are unavailable or too burdened to sustain care at home.<sup>8</sup> Therefore, delivering optimal health care requires the active partnership of caregivers and clinicians (doctors, nurses, social workers, and other health care professionals) in addressing not only the defining cognitive deficits of dementing diseases but also the emotional, behavioral, and physical health problems that frequently complicate management.<sup>9</sup>

Most current initiatives focus on educating clinicians, nurses, and auxiliary health staff about dementia as a disease state or providing caregiver support or training in behavior and mood management for their care recipients.<sup>1,10</sup> Most dementia caregiver assessment tools and interventions address depression, stress, or burden.<sup>11</sup> As fundamental as these efforts are, a programmatic gap exists in assessing and strengthening caregivers' comprehensive dementia health management skills and in facilitating communication between caregivers and clinicians. Bridging this gap requires a systematic approach to valuing and integrating the caregiver as an integral member of the patient's health care team, and providing caregivers with ongoing education, coaching, and clinical oversight as needs change with progression of dementia and other chronic conditions over time.<sup>5</sup>

Consequently, new models of health care delivery are needed that provide systematic, proactive, interventions and target patients and caregivers at high risk for preventable crises.<sup>12</sup> Their

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success depends on engaging and supporting partnerships among patients (as they are able), caregivers, and clinicians, who together manage the patient's health care.<sup>5</sup> We term these interlinked processes "activation"<sup>13</sup> and recognize that they apply to all of the core components of optimal health care for people with dementia: this care is individually tailored, centered on the patient and caregiver as a dyad, multidimensional, and comprehensive in scope.<sup>12</sup> Such complex care requires a method for evaluating caregivers' activation across each dimension as a basis for addressing their needs for health care coaching.

Building on previous studies of caregiver preparedness, engagement, and confidence,<sup>14–16</sup> patient activation for chronic disease self-management,<sup>17</sup> and a comprehensive clinical model for providing health care to patients with dementia,<sup>12</sup> we developed a new measure to assess dementia caregiver activation. This measure, Partnering for Better Health – Living with Chronic Illness: Dementia (PBH-LCI:D), is a self-report questionnaire that systematically assesses caregivers' knowledge and skills across all domains involved in health care management of patients with dementia, as well as their ability to meet their own needs in the face of rising caregiving challenges.<sup>13,18</sup> The present study was designed to assess the reliability and validity of the PBH-LCI:D in a sample of dementia caregivers.

### Development of the PBH-LCI:D

We conceptualized dementia caregiver activation for health care as a multidimensional construct that captures caregiver's knowledge, skills, and confidence in dealing with the range of tasks and challenges inherent in dementia health care management. These include basic understanding of dementia and the patient's other chronic conditions; ability to manage these conditions day to day; understanding and management of medications; recognizing 'red flags,' or sudden changes in the patient's condition that may signify need for clinical evaluation or changes in treatment; confidence in coordinating care and partnering with clinicians; ability to advocate for the patient in health care situations; and aspects of maintaining care for oneself in the context of devoting increasing attention to the care of another person.

An initial pool of 86 questions was derived by integrating the validated domains of the Patient Activation Measure (PAM)<sup>17</sup> with a comprehensive theoretical dementia care model<sup>12</sup> and a new set of dementia management quality measures.<sup>19</sup> The content of questions was further enriched by data from extensive qualitative concept elicitation and cognitive interviews with dementia clinical experts ( $N = 16$ ). Experts were asked to reflect on the domains they considered important in engaging caregivers in patients' health care management, and to identify specific skills that caregivers must develop in order to support optimal health care. The expert panel included practicing clinicians who specialize in dementia: geriatric psychiatrists and nurse practitioners, geriatricians, neurologists, clinical psychologists, and social workers. Interview procedures were repeated with a convenience sample of 35 dementia caregivers who self-identified as primary caregivers and provided daily care at home.

The PBH-LCI:D that emerged from this qualitative development process is a self-rated tool consisting of 35 items (23 'knowledge' and 12 'skills' items), categorized along *a priori* theoretical dimensions, and rated using 5-level Likert type response scale ranging from (1) 'Disagree Completely' to (4) 'Agree Completely,' with an additional response option (0), 'Not my responsibility.' The questionnaire was designed with a 6th grade reading level and has a reading ease of 71.7 (possible scores 0–100, with a higher score indicative of an easier reading level, measured by the Flesch–Kincaid readability test).<sup>20</sup> Cognitive interviews with caregivers

during early phases of questionnaire development used a version with some items worded 'negatively,' such that higher levels of activation would generate lower rather than higher scores and require reverse coding (e.g. "I do not know what medications he/she should be taking"). Caregivers unanimously requested that these items be reworded to conform to the positive framing of the remaining questions. The questionnaire also includes one open ended question and a structured goal setting guide that prompts caregivers to prioritize three content areas they would most like to discuss with the clinician. Possible total scores can range from 0 to 140, with higher scores indicating higher activation. For all items, mean scores between 1 and 4 were calculated for respondents endorsing a non-zero item score. Items with a 0 score ("not my responsibility") were excluded in calculating the sample mean for that item.

### Methods

#### Sample recruitment and characteristics

A convenience sample was recruited from community sources, including support groups led by the Alzheimer's Association of Washington and Minnesota, Senior Services of Washington, local assisted living facilities, memory clinics, dementia workshops, conferences, and dementia advocacy events. Inclusion criteria for participation required that candidates self-identify as a caregiver of a person with dementia, regularly provide hands-on care (e.g. help with everyday activities and medications), and speak and read English at least at a 6th grade level. Recruitment and retention are summarized in Fig. 1. The University of Washington Institutional Review Board approved all research procedures and materials.

#### Data collection procedures

We initially mailed a packet containing 9 measures to 100 of caregivers to collect demographic data (Table 1), PBH-LCI:D, and other measures appropriate for testing concurrent validity and correlations with potential predictors of caregiver activation (Table 2, all measures). We had a return rate of 53%. Participants reported that it was too long and difficult (taking about 90 min to complete). In a subsequent mailing we sent a packet containing the PBH-LCI:D and only 4 additional measures, all of which could be completed in under 30 min (Table 2; measures included in the shorter, core packet are marked \*). The shorter packet was sent to 83 participants and a 92% return rate (Fig. 1). Combined, a total of 130 caregivers returned survey data (53 from the initial expanded mailing and 77 from the second core version mailing). These individuals were all sent a second "re-test" packet 14 days later. Among the 130 caregivers participating, 79 (61%) returned the second re-test survey packet (Fig. 1).

#### Measures

Constructs related to dementia caregiver activation were measured using the Preparedness for Caregiving,<sup>14</sup> the Revised Scale of Caregiving Self-Efficacy,<sup>15</sup> and the Caregiver Mastery and Self-Competence<sup>16</sup> scales. Pertinent caregiver characteristics as stress, anxiety, mood and quality of life were assessed using the Kingston Caregiver Stress Scale, the General Anxiety Disorder Assessment (GAD-7),<sup>21</sup> the Patient Health Questionnaire (PHQ-9),<sup>22</sup> and the Short-form Health Survey (SF-12).<sup>23</sup> Care recipient's neuropsychiatric symptoms were captured using caregiver-reported Neuropsychiatric Inventory Questionnaire NPI-Q.<sup>24</sup> Description of all measures is provided in Table 2.

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