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Homebound Patient and Caregiver Perceptions of Quality of Care in Home-Based Primary Care: A Qualitative Study

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Abstract

Objectives—To assess patient and caregiver perceptions of what constitutes quality care in home-based primary care (HBPC).

Design—Cross-sectional qualitative design; semi-structured interview study.

Setting—Academic home-based primary care program.

Participants—13 homebound patients and 10 caregivers receiving HBPC.

Measurements—Semi-structured interviews explored experiences with a home-based primary care program and perceptions of quality care. Interviews were audio-recorded and transcribed. Qualitative content analysis was performed to identify major themes.

Results—Five major themes emerged related to participant perceptions of quality care: access, affordability, competency, care coordination, and goal attainment. Participants felt reliable, consistent access provided “peace of mind” and reduced hospital and emergency room utilization. Insurance coverage of program costs and coordinated care provided by an interdisciplinary team

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Sarah K. Garrigues: Assisted with study design and interviews, coded subset of interviews, assisted in data interpretation and manuscript preparation

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Christine Ritchie: Designed study, designed interview guide, interviewed patients and caregivers, coded transcripts, analyzed data, assisted with manuscript preparation.

were positively regarded. Interpersonal skills and technical abilities of providers influenced patient perception of provider competency. Assessing and helping patients attain care goals contributed to perceived quality care.

Conclusion—Patients and caregivers associate high-quality HBPC with 24/7 access to affordable interdisciplinary providers with strong interpersonal skills and technical competency. These results expand on prior research and are concordant with HBPC goals of 24/7 access to multidisciplinary teams with the goals of reduced emergency and hospital utilization. HBPC programs should be structured to optimize access, affordability, coordinated care, and goal ascertainment and alignment. Quality indicators should be created and validated with these patient and caregiver views of care quality in mind.

Keywords

Home-based primary care; quality indicators; qualitative study; patient and caregiver perspective

Introduction

Approximately 2 million community-dwelling older adults in the United States are homebound due to a combination of chronic illness and functional impairment.^{1, 2} Homebound older adults use health services at high rates and are more likely to have been hospitalized in the past year compared to their non-homebound counterparts.³

Home-based primary care (HBPC) provides comprehensive, interdisciplinary, longitudinal care at home for homebound patients who cannot access typical ambulatory-based care.⁴ In 2011, 11.9% of homebound individuals received HBPC.¹ HBPC reduces hospitalizations and nursing home admissions, saving an average of approximately \$3,000 per patient beneficiary per year.^{5, 6}

Despite the increasing use of HBPC and evidence of its effectiveness, there are no appropriate or widely used quality indicators for HBPC.⁷ Quality measure creation and implementation is a priority given the recent passage of the Medicare Provider Payment Modernization Act, which will assess (and reimburse) providers on quality of care, resource use, and clinical practice improvement activities.⁸ Quality measures should be created with an understanding of patient and caregiver concerns and preferences.⁹ However, little research has been performed on patient and caregiver perspectives regarding quality of HBPC.^{10, 11, 12}

This study aimed to assess and describe the perspectives of homebound patients and their caregivers regarding what represents quality of care in HBPC in order to inform the development of patient-centered quality indicators for HBPC.

Methodology

Study Design, Setting, and Participants

Patients and caregivers were recruited from an academic urban HBPC practice at the University of California, San Francisco that provides care to approximately 225 homebound

older adults annually. Patients and their self- or physician-identified primary caregivers were eligible for participation. Eligibility criteria included ability to conduct an interview in English and willingness to be interviewed in the home or by phone. Exclusion criteria were: moderate to severe cognitive impairment (as determined by their primary care physician), aphasia, and/or profound hearing impairment. Caregiver participants were identified as a dyad with patient participants, or as a proxy for patients who were unable to participate.

Enrollment

Between May and June 2013, primary care physicians in the program were asked to identify any patients and/or their primary caregivers who met the eligibility criteria. The practice's patient coordinator contacted potential participants by telephone between June and July 2013. Purposive sampling was used in order to obtain a diverse sample of participants by race, socioeconomic status, and living status (alone or with others). After interviewing 23 participants, no new themes arose and participant recruitment was concluded.

Data Collection and Analysis

Semi-structured interviews were conducted by the primary author (A.S.) at the homes of participants or by telephone, based on participant preference. Interviews lasted a mean of 43 minutes (range 18 to 95 minutes). Patients and caregivers were interviewed separately when possible.

The interview guide was developed based on a literature review of similar studies ascertaining patient and caregiver perceptions of quality care in settings other than HBPC, and on the Health and Human Services Multiple Chronic Conditions key measurement concepts.¹³ Several questions focused on patient characteristics, including demographic information, social engagement, and functional status. To determine functional status, participants were asked if they needed no help, some help, or total help completing activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Questions focused on participant experiences with their HBPC medical providers, including what they considered to be “good” care versus “bad” care (see Appendix for the complete interview guide).

Chart review was used to assign a Cumulative Illness Rating Scale for Geriatrics (CIRS-G) score, a quantitative rating of comorbidity and chronic illness burden.¹⁴

Interviews were audio recorded and transcribed verbatim. Investigators conducted qualitative content analysis using a mixed inductive and deductive approach.¹⁵ The initial coding framework was derived from an adapted version of the Health and Human Services Multiple Chronic Conditions key measurement concepts.¹³ Additional codes and subcodes were developed when new concepts arose from the interviews that were not represented in this initial framework. Atlas.ti was used for coding and analysis.

Two researchers (AS, SG) coded a subset (22%) of transcribed interviews independently. Coding decisions and discrepancies (less than 10%) were then discussed among all authors until consensus was reached. The finalized codebook was used for the remainder of the interviews.

Ethical status

This study was approved by the UCSF Institutional Review Board.

Results

Of 151 patients in the program, 22 were contacted to participate in interviews. Thirteen agreed to participate, 5 declined, and 4 could not be reached. Sixteen caregivers were contacted to participate, with 10 final participants, 2 declining, and 4 unable to be reached. Participant and caregiver demographics are presented in Table 1.

Multiple themes emerged in participant descriptions of high quality HBPC. This paper focus on themes that providers and health care systems can impact by modifying the way care is provided or structured to improve the patient and caregiver experience. Illustrative quotes are provided in Table 2.

Access to care and providers

Access was highly valued by patient and caregiver participants in interviews. Participants appreciated the ease of having someone visit them in the home, given challenging transportation logistics and expense. The opportunity to reliably and consistently access a provider via phone, email, and in-person visits was also important. For example, one caregiver said, “oh, she's so responsive. I could e-mail, text... call...I've always been able to reach someone who's on call, or the nurse practitioner fills in sometimes.” (Phone access is provided via HBPC patient coordinators. After hours calls are routed to a call center. If the issue is urgent, the operator pages the provider on call.)

Patients and caregivers described a feeling of “peace of mind” knowing that they had someone to reach if anything were to happen. As this caregiver said,

“It gives us peace of mind knowing that we have somebody to – the phone right there, a phone call away to ask and have solutions for what problems and answers to all of our questions... you can think better when you have peace of mind.”

Many participants felt they avoided hospitalization by triaging problems with phone calls to their provider, and receiving home visits if needed. One patient relayed his experience:

“I have had what at first appeared to be an intestinal blockage, which prompted a call from me to them. And ... nurse practitioner came out and the first step was a laxative and that cured the problem, otherwise, I would have had to go into the hospital for observation.”

Participants identified gaps in access to physical therapy, dental care, and specialists. Some patients desired access to long-term or preventive physical therapy. Others complained of limited access to dentists or specialists.

Affordability of care

Affordable care was frequently mentioned as a valuable aspect of the medical care received in the home. This HBPC program accepted Medicare and Medicaid, and every participant

said their medical care was affordable, even if other elements, such as paid caregivers, were not.

Avoiding transportation costs to a typical clinic was also a benefit of receiving HBPC. Homebound and wheelchair dependent patients had tremendous difficulty affording transportation. They often had to call an ambulance in order to leave the home, as this patient noted: “I live upstairs in a Victorian with many, many staircases. It takes two ambulances to cope with it, because of the staircase... it's a tremendous expense which is not covered by my insurance”

Provider Competency—Provider competency, including both interpersonal and technical skills, was associated with high quality care. Interpersonal skills, such as patience and listening, were strongly linked to participant satisfaction and assessment of the quality of care they were receiving. This caregiver stated:

“I don't feel rushed. They listen and they take the time to clear my – any doubts and answer any questions... And you know with my English sometimes I have to ask again. I have never felt like they... are bothered because I ask again.”

Technical competency, especially specific to medical issues of older adults, such as judicious medication management and clarifying goals of care, was important to participants. This patient discussed his experience with the doctors that visited him in the home:

“They're good, well-trained people. You can judge them from their performance, the questions they ask, and the suggestions they make...So, I'm in good hands. That's the way you feel about it: confidence with your medical people.”

Care Coordination—Care coordination – with other providers, care settings, and with medical equipment agencies – was important to participants. Interdisciplinary home safety assessments were often mentioned, as was coordination with the pharmacy for refills and controlled medications. This patient discussed the different providers that had visited his home:

“Well, when I first got a visit from a team social worker and occupational therapist and physical therapist, the occupational therapist looked at my bathroom to make sure I had grab bars, which I already had.”

Patients appreciated having a primary care provider to help them make decisions about which specialist to visit, and subsequent medical management. Care coordination for arrangement of stays at and transport between different care settings was also mentioned, such as if a patient had to go to a nursing home for rehabilitation or respite.

Goal Attainment—Evaluating and addressing patient goals of care was an important aspect of participant perceptions of high quality of care. Being able to stay in the home for as long as feasible was a common goal. Participants also emphasized achieving comfort, especially in regard to chronic conditions, as this caregiver relayed:

“They're dealing with his quality of life. I mean he got to a certain point that there wasn't any point in trying to cure him of this – whatever, all his ailments... Getting

him off a lot of his medications sort of made his health better... That's what it was about.”

Discussion

In semi-structured interviews, patients and caregivers receiving HBPC described quality care as being related to access, characteristics of the providers, and the services provided. Important aspects of access included reliable availability of providers 24/7 either in person, or via phone and email, and access to the type of care that would be provided in a medical office, including basic diagnostic tests. Participants stated this access gave them “peace of mind” knowing that they could reach a provider to triage any problems that might arise and thus potentially avoid emergency room trips. Affordability of care was closely linked to access; providers visiting the home saved on transportation costs to a clinic. Provider characteristics were meaningful to participants, especially interpersonal skills and technical competency in managing patients with multiple comorbidities. The services provided by HBPC that were important to patients included care coordination and clarifying and aligning patient's treatment with their goals. These findings are consistent with a recent study of a Veteran's Administration HBPC program, in which patient and caregiver participants similarly appreciated “access, education, and continuity of care, which they felt contributed to fewer exacerbations, emergency visits, and hospitalizations.”¹²

Constant (24/7) access to on-call providers is a basic tenet of HBPC.^{12, 16} Access can often be offered via phone triage; in one study, urgent visits or emergency department visits were only required about five percent of the time.¹⁷ Participants perceived that emergency room visits and hospitalizations decreased because they were able to access someone by phone or have a physician visit when issues did arise. Several studies have found decreased hospitalization and SNF admissions with HBPC programs, confirming patient perceptions in this study.^{12, 16, 18} Participant preferences for provider traits matched a prior survey exploring key qualities that influence patient satisfaction: communication, access, interpersonal skills, and care coordination were identified as the core provider qualities.¹⁹

Patient and caregiver perceptions of what constitutes high quality HBPC suggest a number of changes in health service delivery that could improve patient-centered HBPC. Twenty four-seven access should be prioritized, as it was critically important both to participant perception of quality and to reducing emergency room and hospital utilization. Effective interpersonal skills, especially patient-physician communication, are known to improve health outcomes and should be a focus for clinicians.²⁰ Technical competence can be improved by increased geriatrics training – whether primary or specialized. A set of competencies relevant to home-based practice should be incorporated into educational curricula and accreditation requirements.^{21, 22} General guidelines are available to assist clinicians in taking care of patients with multiple comorbidities to adequately address treatment burden and goals of care.^{21, 22} Care coordination is a critical component of HBPC, defined by the AHRQ as purposefully organizing patient care and sharing information among all participants involved to achieve safer and more effective care.²³ This also coincides well with helping patients and caregivers realize their goals of care by identifying goals and guiding shared decision making.²⁴ Care coordination and goal-oriented patient

care should be a priority for all HBPC providers, and incorporated into quality metrics accordingly.

Limitations

A limited number of patients were deemed eligible, which narrowed the available participant pool towards patient participants with less frailty and comorbidity. Proxies may have ameliorated this issue by having someone to speak for patients with more severe impairments, including dementia. Patients were not informed their PCP recommended them for the study, though patients who declined to participate may have had alternative views on the program that were not reflected. However, the sample was fairly diverse, both with regards to race/ethnicity, educational attainment, and disease burden, which is representative of other urban HBPC programs.²⁵ Different HBPC programs would need to be studied in order to get a full spectrum of responses, both positive and negative.

Conclusion

The key themes of access, affordability, and technical and interpersonal skills provide a framework for which to consider what patients and caregivers consider good quality care, and how to achieve it. The structural organization and set up of HBPC programs determines the degree of access patients and caregivers have to their medical providers. Having constant access was critical in perception of access and influenced health care utilization, as participants could reach a provider to triage their problems and advise them appropriately. Affordability was linked to program acceptance of Medicare, few out-of-pocket fees, and avoiding transportation costs. Interpersonal skills, especially listening in a non-“rushed” manner, was important to patient and caregiver perception of providers. Geriatrics competency, either via primary or specialized training, was critical to delivering goal-oriented medical care to a population with complex comorbidities.

These results expand on existing research, and bolster efforts to standardize HBPC programs to have 24/7 access to multidisciplinary teams with the goal of reduced emergency department and hospital utilization. Many of these tenets are represented in the Independence at Home legislation and demonstration project.⁶ Work to create and implement quality measures for HBPC that incorporate patient and caregiver preferences is underway by the National Home-Based Primary Care and Palliative Care Network.⁹ The Network has developed a set of quality indicators for HBPC to be used within a practice-based registry. This study emphasizes that patient-centered care can be advanced by using quality indicators that assess patient access and their satisfaction with their providers' competency and that measure efforts towards care coordination and goal-oriented care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1
Demographic Information of Patient and Caregiver Participants

Characteristic	Patients (n=13)	Caregivers (n=10)
Women	62%	50%
Age (years, mean)	85	64
Race		
African American/Black	0%	20%
Asian	8%	30%
Caucasian/White	85%	40%
Hispanic	8%	10%
Highest Educational Level		
High school diploma or less	30%	10%
Some college	8%	30%
Completed college	15%	40%
Graduate degree	46%	20%
Patient Characteristics (n=13)		
Cognitive impairment	38%	
Living status		
Alone	9	
With others	4	
Home care provider or attendant		
Yes	7	
No	6	
Medications (total, average)	10.2 (± 3.7)	
Dependent ADLs (average)	2.3 (± 2.3)	
Dependent IADLs (average)	5.0 (± 1.5)	
CIRS categories endorsed (average)	6.8 (± 2.5)	
CIRS score (average) ^a	13.7 (± 5.0)	
Cumulative Illness Rating Scale Severity Index (average, 0-4) ^a	2.0 (± 0.4)	
Caregiver characteristics (n=10)		
Relationship to patient		
Relative	8	
Paid	2	

Characteristic	Patients (n=13)	Caregivers (n=10)
Number of caregiving hours per day (average)	11.8 (\pm 9.4)	
Number of years as primary caregiver (average)	6 (\pm 2.8)	

^aThe CIRS-G evaluates 14 organ systems. The severity of comorbidity in each organ system is based on a scale from 0 to 4 (0, no problem; 1, Current mild problem or past significant problem; 2, moderate disability requiring “first-line” therapy; 3, severe, constant, or significant disability, or “uncontrollable” chronic problems; 4, extremely Severe/immediate treatment required/end organ failure/severe impairment in function). The total score is calculated by adding together all the categories. The severity index is calculated by the total score divided by the number of categories endorsed.

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Table 2
Patient and Caregiver Views of Home-Based Primary Care

Theme	Example
Access	<p>You know, and it's just so much easier to not have to take him to the doctor's office. Because, you know, he's getting so less mobile that – even with one of his caregivers with him, it's really hard to take him downstairs, get him into the car. And it just takes so much out of him. Even with it being on the ground floor, it was so hard on him, just terrible. He couldn't even – then when he's in the waiting room, he had trouble getting out of the chair, and so he'd just be kind of – I'd be exhausted, too, but he'd really be exhausted. - Caregiver</p> <p>They also come on a regular basis every month to actually check on her and they call to find out how she's doing and every time she falls ill they always do a follow up visit. They check the blood pressure, the oxygen, they check the whole body to find out. - Caregiver</p> <p>It's a 24 hour thing, so for instance they're already off there's always a doctor on call that is wonderful because even in the middle of the night I can give them a call. They're very, very fast at responding, I was very surprised. - Patient</p>
Affordability	<p>Yeah, not having to – excuse me – provide transportation to and from the doctor's office has been tremendous. 'Cause the one time we had to go, we had to call an ambulance, and it was like 900 bucks. Shoot, I coulda bought me a old ambulance." But we needed those youngsters to get her up the stairs. - Caregiver</p> <p>Well, I guess this is all covered with – by insurance. And so, you know, that's – if I had gone with one of the concierge ones, I'd have to – they – since they don't cover it, we would have had to pay out of pocket. – Patient</p> <p>These other doctors...would not accept Medicare or MediCal. They said that I had to pay for the visit. And the visit was like \$200 something per visit. And I said, 'No, impossible. We cannot afford that.' These doctors accept the Medicare and MediCal that my mother has so it's really, I guess really perfect - Caregiver</p>
Provider competency	<p>They're pretty thorough. Again, the same thing that he really appreciated, they seem to be very kind and respectful. I don't feel rushed, so that's a nice thing. I really feel like they take a lot of time with him, which, you know, is unusual in this day and age. - Caregiver</p> <p>You know what I think for a medical person you need knowledge. You need knowledge without knowledge that wouldn't work, because other people are also nice. But if both together that's what I appreciate. - Patient</p> <p>They've been very prompt about coming here. They've taken a lot of time with him. They seem very knowledgeable about the needs of elderly people. Good bedside manner. Very kind and respectful towards him and towards me as well. So, that's – I appreciate that. - Caregiver</p>
Care coordination	<p>She coordinates the medical care. So, that's huge. So, I don't have to go find a doctor, locate somebody if he has another kinda problem; she does it. - Caregiver</p> <p>Well, I mean they're in constant touch with the staff [at the assisted living facility]. So, they're informing him what they have to do and what the needs – you know, what his – you know, if his condition changes and they have to monitor him more closely; or things are just going fine, and they don't have to monitor him. - Caregiver</p>
Goal attainment	<p>Usually I'm here, but she sometimes will try to get him alone, and she makes it a point to let him know that he can talk to her and tell her if he feels he's just so fed up that he does not want to continue dialysis. So, she lets him know that he can let her know that, even if he doesn't want to tell me. - Caregiver</p> <p>They accept the patient where they're at, and they want to give the patient whatever quality of life that they express they feel they have or want to have, and they're not pushing their own agenda. - Patient</p>