Health Care Home: Experiences and Criteria in the Pathways to a Healthy Bernalillo County Program

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SUMMARY

Background. One of the long-term goals of Pathways is that people in Bernalillo County will have a health care home. The definition of the health care home in the context of the program and target population of vulnerable, uninsured adults, however, has not yet been articulated. It is important to provide specificity to the concept in order to assess progress toward this goal.

Aims. (1) Determine what would be an acceptable and meaningful definition across multiple levels of engagement that could be the reference for assessing Pathways' health care home goal.
(2) Capture the (a) current experiences of vulnerable adults in accessing and using the health care services in Bernalillo County, (b) barriers encountered and (c) perceptions on how health care should be available and configured.
(3) Capture the perceptions of health care clinic providers and administrators who care for vulnerable adults about (a) what is needed to serve vulnerable adults, (b) the extent the system should capture elements of the patient-centered medical home, and (c) what barriers presently constrain the development of needed elements.

Methods. A review of definitions of the patient-centered medical home being used by the Agency for Healthcare Research and Quality, National Committee for Quality Assurance, and American Academy of Family Physicians led to the following definition for use in the context of the Pathways goal: a clinic-based health care setting where vulnerable adult patients have regular health care providers and where the care is accessible, coordinated, comprehensive, delivered with quality and safety, and patient-centered. This definition was summarized into a list of specific characteristics or elements used in this study in order to organize and analyze the data.

Six focus groups comprised of community participants (adults with high risk backgrounds similar to Pathways clients) and Pathways navigators were convened to describe recent experiences attempting to obtain or obtaining health care, express their thoughts on the kind of care that is important to them, and to react to the elements of the defined patient-centered medical home. Verbatim transcripts of these discussions were analyzed for content pertinent to the elements of the patient centered medical home and whether the comments reflected positive, negative, or mixed experiences. They were also analyzed to determine the most frequent barriers to care. Participants were questioned about the importance of the individual elements of the patient-centered medical home. They were asked individually to assess the extent to which their personal health care encounters reflected the full expression of the elements of the patient-centered medical home.

In addition, medical providers and clinic administrators representing local healthcare organizations that serve vulnerable adults were interviewed to determine what elements of care were seen as needed to serve these patients, and to respond to the elements that define the patient-centered medical home. Each was asked to assess how the study definition of health care home is used in her/his clinic , challenges and barriers related to the definition, and

to describe places where this definition of health care home is being implemented in Bernalillo County.
Findings and conclusions. (1) Having access to a health care home is viewed as desirable by participants at all levels of engagement - vulnerable adults, community health navigators, and primary care physicians and clinic administrators- and should be a goal applicable for vulnerable adult patients. The clinical directors and administrators of the sites delivering services are familiar with the elements of the patient-centered medical home, accept their appropriateness, are actively trying to incorporate or build them into their respective clinical sites, and specifically agree that they are appropriate in the context of the vulnerable adult and Pathways. They note that structural barriers, particularly concerning how operations and staffing are financed, impede the development of the health care home model. The median score for their global assessment of local clinics achieving the elements of the health care home was only 25%. (2) For most vulnerable adult patients, the currently available primary care falls far short from being a health care home. Community participants and navigators entered the focus groups largely unfamiliar with the idea of a health care home. Several accepted the definition as desirable, but were decisive in stating that this model is not presently available to them. Participants' accounts of their own experiences engaging the care process and navigators' accounts of clients were more negative than positive across many elements of care. Median global assessment scores referenced against full attainment of the health care home as defined was 44% for vulnerable adults and 40% for community health navigators. Barriers for patients include lack of money or insurance, perceived discrimination tied notably to race and stigmatization of being poor, lack of legal documentation, limited abilities to communicate or understanding of how to use the system, and lack of available and timely appointment slots. (3) Community participants and navigators cited certain specific clinical settings as being better able to address issues that relate to patient-centered care, care for the whole person, and coordinated care. These clinics are mission-driven and distinctive in existing specifically to provide services to vulnerable adults and families. At these sites, barriers to access and to the utilization of services do not exist, and staff conscientiously anticipate clients' limitations and guide the patient through the clinical process. At one of them, an exit interview is designed to assure that expectations for treatment follow up a are clear and feasible for the patient, and to address any questions or concerns the patient may have. These particular clinics depend only minimally on fee-for-service payments. (4) Having an advocate may be essential for health care home success. In the clinic setting, the vulnerable patient needs to be identified at entry, special coordination to reduce barriers should take place, and the elements of patient-centered care assessed and addressed throughout the clinic experience. Community participants' stories repeatedly cited instances reflecting the person's difficulty accessing care, a lack of understanding of how to successfully use the system, and a lack of understanding of the clinical process. The complications of co-occurring illnesses (including mental health problems) and the confounding overlay of suspicion and skepticism about the effectiveness of care, fear, frustration, or anger all come into play. At times the plans for follow up simply do not fit the realities of their lives. Many of these patients need an advocate at their side.

The advantage of having an advocate was also strongly supported by community members and Community Health Navigators.

INTRODUCTION

One of the four Pathways goals is, “People in Bernalillo County will have a health care home.” In the context of Pathways, “people” means vulnerable adults in need of health care but who are not regularly accessing health care except in emergency rooms or similar settings. “Vulnerable” means there are notable personal or situational circumstances that place the person at increased risk.

A definition of “health care home” as used in this Pathways goal, however, has never been clear. The health care home might mean anything ranging from the full-blown model of the patient-centered medical home down to a simple demonstration of achieving a single scheduled follow-up visit with a given clinical provider. The latter is what Pathways uses as an operational benchmark of success in getting clients having no organized clinical care into a setting where continuity is at least possible.

The purpose of the Health Care Home Study was to determine what would be an acceptable and meaningful definition that could be the reference for assessing Pathways’ health care home goal and that made sense at the three levels of program engagement: Pathways clients; community health navigators; and clinical practitioners and administrators presently active in primary care. This inquiry was felt to have implications useful for other projects that are similar in nature and contribute to the local and national discussion about how the health care home can appropriately be applied to vulnerable adults.

The study reported here is based on information gathered from a sampling of community participants similar to vulnerable adults participating in Pathways, from Pathways Navigators, and from a sampling of providers, clinic directors and administrators of primary care clinics in Bernalillo County that such adults might use.

An important aspect of the study sought to capture the current experiences of such adults in accessing and using the health care services in Bernalillo County including barriers encountered and their perceptions on how health care should be available and configured in general and specifically the extent the system should capture specific elements of a patient-centered medical home. The experiences and insights of the navigators in their efforts to connect vulnerable adults,(Pathways clients) to a health care home were also obtained for the purpose of meeting this goal.

The third goal was to capture the perceptions of health care clinic providers and administrators of what is needed to serve vulnerable adults, the extent the system should capture elements of the patient-centered medical home, and what barriers presently constrain the development of needed elements.

This study examined the status of care for vulnerable adults in Bernalillo County. It was explicitly not intended to be a direct examination of the experience of Pathways clients or an examination of any particular clinic or hospital.

APPROACH

The approach was to use focus groups to gather views about experiences accessing and utilizing primary care services from community participants thought to be representative of the adult populations from which Pathways clients come. Participants were recruited from four groups in Bernalillo County:

- Native Americans
- Spanish-speaking immigrants from the Southeast Heights
- Spanish-speaking immigrants from the South Valley
- Formerly incarcerated persons

In addition, two focus groups were drawn respectively from English-speaking and Spanish-speaking Pathways community health navigators. Navigators would comment on the experiences of their clients using or attempting to use primary care services, as well as what they felt was important in health services and delivery to meet the needs of vulnerable adult patients.

Individual interviews were obtained from clinic directors and/or administrators of primary care clinics and other clinics that specifically offer services for the homeless and for immigrants. All clinics are located in Bernalillo County.

METHODS

The study (#12-286) was formally approved in August 2012 by the UNM Health Sciences Center Human Research Protections Office.

Defining the elements of the health care home.

In order to frame the concept and facilitate the collection, organization, and analysis of data in this study, the working definitions of the patient-centered medical home used respectively by the Agency for Healthcare Research and Quality, National Committee for Quality Assurance, and American Academy of Family Physicians were reviewed. Drawing upon these definitions, elements of a health care home were identified (Table 1).

The definition of the health care home used in this study aligns generally with the patient-centered medical home and is as follows: a clinic-based health care setting where vulnerable adult patients have a regular health care provider and where the care is accessible, coordinated, comprehensive, delivered with quality and safety, and patient-centered.

Table 1. Elements of a Health Care Home.

Access and availability
Patient-centered care (addressing the patient's point of view and perceived concerns)
Whole person care (extending beyond focus only on current disease or symptom management)
Coordinated care: • Continuity of care across time, place, and provider

• Communication/awareness of information across system of care and between provider and patient • Organization, operational functionality and timeliness in the system of care
Quality being a prioritized and expected outcome
Safety being a prioritized and expected

Participant recruitment.

The recruitment of community participants addressed specifically the four groups mentioned above. To participate, community participants needed to have a high school education or less, an annual household income of $40,000 or less, and used a primary care clinic in the last year. Also, they had a mix of different types of health insurance, but the majority needed to be uninsured. Specific inclusion criteria for the four community participant groups, as well as criteria for the two navigator groups, and the provider interviewees are in Table 2. Demographic targets for the recruitment for the community participants are in Table 3.

Table 2. Participants: Inclusion Criteria by Group

Group Recruited	Inclusion Criteria
Native American	Have lived in Albuquerque or another part of the county not including Isleta Pueblo for at least one year.
Hispanic immigrants – South Valley	• Latino/Hispanic • Originally from a Spanish-speaking country • Lived in the U.S. for no more than 10 years • Language most spoken at home: Spanish or mix of Spanish and English
Hispanic immigrants – Southeast Heights	
Formerly incarcerated	• Out of jail or prison for at least 1 year but no more than 5 years • Not detained pending arraignment, trial, or sentencing • Not under court order as an inpatient in a hospital or alcohol/drug treatment facility as an alternative to incarceration • Not wearing a court ordered monitoring device • Not in a court ordered juvenile detention residential setting
Navigators	Currently work as a navigator for the Pathways program.
Providers and administrators	Work as a medical provider, medical director, or clinic administrator at a primary care facility in Bernalillo County that accepts and offers care to vulnerable adults.

Table 3. Demographics of Community Participants: Inclusion Targets and Actual Distributions.*

		Inclusion target	Actual distribution % and (number)
Age	18-19 years 20-49 years 50+ years	10% 80% 10%	29% (10) 57% (20) 14% (5)
Sex	Male Female	50% 50%	66% (23) 34% (12)
Annual household income	>$10,000 $10,000-$20,000 $21,000-$30,000 $30,000-$40,000	50% 30% 20% (none)	57% (20) 37% (13) 6% (2) (none)
Years of school completed	Less than high school diploma With high school diploma	55% 45%	Elem. 11% (4) Mid. sch. 43% (9) High sch. 46% (16)
Health insurance	No insurance Public assistance Medicaid Other	55% 30% 15%	None 54% (19) UNM Care 26% (9) Medicaid 9% (3) SCI 6% (2) Molina 6% (2)
No. times used clinic in past year for self of adult member of family	(No clinic visits) 1-2 3-5 6+	(none) 33% 33% 33%	(none) 37% (13) 23% (8) 40% (14)

*Includes all: Native Americans, Hispanic immigrants from South Valley and from Southeast Heights, and formerly incarcerated.

The field researcher was responsible for community member focus group recruitment and recruiting methods included distributing flyers, making announcements, and engaging the assistance of various gatekeepers online and by telephone. Efforts particularly targeted the following:

- Geographic areas (for Southeast Heights and South Valley participants)
- Known usage locales (bus stops, homeless shelters, food banks, immigrant centers, community centers, substance abuse centers, and Laundromats)

Snowball methodology was used as opportunities arose.

Focus groups and interviews.

All participants provided verbal consent and were given a copy of the confidentiality measures and contact information as per study requirements. Community participants received $40 gift certificates to offset any personal costs that may have been incurred such as transportation or childcare.

The focus group discussions and the interviews began with semi-structured, open-ended questions and discussion. When appropriate, the facilitator followed up with probing questions when needed to assure that each of the various elements attributed the patient centered medical home were at least introduced. Participants were encouraged to describe personal experiences (both good and not good) with health care offered in primary care clinics and finally to describe what they would like to have in the ideal.

At the end of the group session or interview, participants were asked to react to a brief definition of the patient-centered medical home in terms of its suitability to the care for themselves personally in the case of the community participants, or in terms of its suitability for "vulnerable adults" such as targeted by Pathways in the case of the Navigators and the clinic directors and administrators. Also, participants were asked to mark on a linear scale where they felt health care for vulnerable adults currently lies with respect to meeting the definition, the line representing a left-to-right continuum from not-at-all to fully meeting the definition.

Focus groups were recorded and verbatim transcripts prepared, with Spanish transcripts translated into English. Responses from individual interviewees were prepared from the interviewers written notes.

Analysis.

Content material from the focus groups relating to primary care experiences and perceptions of ideal care was analyzed independently by two readers with respect to frequency of remarks relating to each of the elements of the patient centered medical home and to frequency of remarks relating to barriers to access and/or to utilization. Repetitions from the same person were not added to the frequency counts. The counts were sorted by whether remarks were negative or positive reflections about the experience, or whether mixed/indeterminate. A "mixed" comment might have aspects or include instances that were both positive and negative. Included as negative remarks were comments about what one would like to have had as long as the remark was given in the context implying that something had not been available or had not happened when there was a perceived need for it. Remarks in response to a question about what a participant would like to see in a system of care were separately analyzed with respect to frequency relating to the elements of the patient-centered medical home. The two readers met in order to resolve discrepant counts and assignments among the categories. Typically the discrepancies occurred because the elements in the categories are not mutually exclusive.

Content material from the interviews of clinical directors and administrators were scored by noting the inclusion (or not) of the elements of the patient-centered medical home in responses to questions that were asked in sequence, including: "What do you think are the most important things for vulnerable adult patients when receiving health care at a clinic?" "What does the term 'health care home' mean to you?" "What should a health care home look like for adult patients with complex needs?" and "Is it realistic?" and "What are barriers to having this?"

A median and average global score of the linear scale was assessed by assigning the measured distance of the mark along the linear scale its score on a range of zero to 100.

RESULTS

The numbers of community participants and group characteristics for each of the focus groups are shown in Table 3, above.

With few exceptions, the results from each of the focus groups were similar. The percent distribution and aggregate tallies of community participant and navigator comments (negative, positive and mixed comments combined) related to the elements of the health care home are shown in Table 4. Issues of access were dominant. Navigators gave comparatively less attention to the elements of the care process, perhaps reflecting their jobs being more focused on getting clients access into care in the first place. Across all the focus groups comments were predominantly negative (See Table 5).

Table 4. Percentages of All Comments* by Community Participants and by Navigators About Clinic Experiences by Health Care Home Element.

Health care home element	Frequency %	Frequency count
Access	36%	146
Patient-centered	21%	87
Whole-person	13%	52
Continuity	11%	45
Communication/awareness	7%	27
Organization	6%	26
Quality	4%	17
Safety	2%	8
Total	100%	408

* Unduplicated comments; whether positive, negative, or mixed.

Table 5. Percentages of Comments in All Focus Groups by Whether Positive, Negative, or Mixed.

Scoring of comments	Percentage
Negative	64%
Positive	22%
Mixed	14%

The percent distributions of the elements of the health care home within the negative, mixed, and positive categories respectively are shown in Table 6. Access dominates all categories, particularly in the negative. Within the positive comments, respondents commented disproportionately about patient centered care and treating the whole person. The positive comments came from persons with insurance coverage and from persons using facilities that specifically target homeless or immigrant populations.

Table 6. Total Numbers and Percentage of Negative, Mixed, and Positive Comments of Community Participants and Navigators (Combined) about Experience Using or Attempting to Use Primary Health Care, by Health Care Home Element.

	Negative comments (n=262)	Mixed (n=56)	Positive (n=90)
Access	38%	45%	24%
Patient-centered	17%	21%	33%
Whole-person	10%	18%	18%
Continuity	13%	5%	10%
Communication/awareness	8%	5%	3%
Organization	8%	0%	4%
Quality	3%	5%	7%
Safety	3%	0%	0%
Total	100%	100%	100%

Ranked order of frequency of comments by type of barriers to access and utilization of care is in Table 7. Most commonly cited were the barriers related to inability to pay or lack of insurance. Other barriers frequently mentioned related to perceived stigma centering on race (particularly evident in the Native American focus group), on being poor, and lacking legal documents (particularly evident in the immigrant focus groups). Other barriers included the length of time before an appointment could be scheduled and the health care system’s inability to adequately accommodate an individual who has difficulty navigating the inherent complexities of the care process. Examples included individual inability to understand language, signage, and print information or cope with or endure long delays before being seen. Problems with transportation were infrequently mentioned.

Table 7. Ranked Order of Frequency of Comments in Focus Groups by Type of Barriers to Access and Utilization of Care.

Rank	Type of barrier
1	Ability to pay; lack of insurance
2	Discrimination, racism, stereotyping
3	Legal documentation (not having)
4	Literacy level, education level, language
5	Transportation

Lack of access to mental health services, continuity in mental health follow-up and the lack of availability of counseling were also mentioned by several community participants and navigators.

Native American participants noted the limitations of types of services available at the Indian Health Service facility in Albuquerque. Frequently mentioned were instances of struggling to obtain eligibility for discounted services at other facilities, being told that they should find care at an IHS facility or a tribally run facility, even when not available. Native American participants contributed disproportionately to race being a barrier to access or a factor in the obtaining care.

Focus groups were presented with the definition of the health care home in terms of the patient-centered medical home. They understood the elements and many expressed that these elements were not descriptive of their experiences in the past year. While they would like to have care as described, most doubted that it would be available to them in the foreseeable future. Responses to a question about what among these elements they would like to see are shown in Table 8.

Table 8. Percent and Numbers of Comments by Community Participants and Navigators About What Would Be Important, by Health Care Home Element.

Health care home element	Frequency %	Frequency count
Patient-centered	23%	43
Whole-person	21%	39
Access	17%	32
Organization	11%	20
Communication/awareness	10%	18
Continuity	7%	13
Safety	6%	12
Quality	5%	10

When asked what their responsibilities are as patients in using a functioning medical home, they mentioned such things as taking care of the health care home (getting involved, letting people know it is a good place, supporting the team), taking care of oneself, keeping appointments, paying for what one can, and clearly communicating one's needs.

The opening question for clinical providers and administrators (prior to a specific discussion about health care homes) asked what they felt to be important in providing care to adult patients with complex needs. Their responses are summarized in Table 9, tabulated in terms of the elements of the health care home.

Table 9. Frequency Percentages of Comments by Providers and Administrators (Combined) About Important Elements of Care for Vulnerable Adults (Prior to Discussion of Definition of Health Care Home).

Rank	Health care home element	Frequency %	Frequency count
1	Access	30%	20
2	Whole-person	25%	17
3	Patient-centered	18%	12
4	Continuity	9%	6
4	Communication/awareness	9%	6
6	Quality	4%	3

6	Organization	4%	3
8	Safety	0%	0

When provided with a definition of a health care home that included the elements of the patient-centered medical home, all clinical providers and administrators expressed familiarity with the concept and indicated that they were currently working toward achieving most of these elements. The most frequently cited elements they felt important and to be ideal goals for the Health Care Home are in Table 10.

Table 10. Frequency Percentages of Comments by Providers and Administrators (Combined) About What Would Be Ideal for Adult Patients with Complex Needs by Health Care Home Element.*

Rank	Health care home element	Frequency %	Frequency count
1	Whole-person	25%	41
2	Patient-centered	18%	30
3	Access	18%	29
4	Continuity	17%	28
5	Organization	14%	22
6	Communication/awareness	4%	7
7	Quality	3%	5
8	Safety	1%	1

* Comments by providers and administrators made during interview prior to specific introduction of the definition or prompting about the elements of the health care home.

Most acknowledged that they presently fell short of delivering on these goals and cited structural and attitudinal/cultural barriers holding them back. (See Table 11)

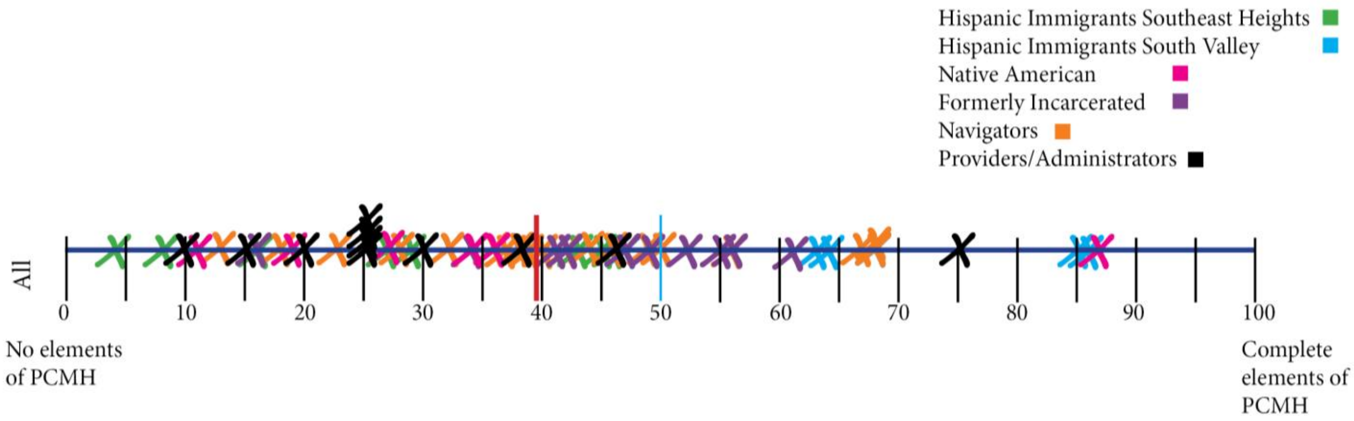
Table 11. Examples of Barriers Reported by Providers and Administrators to Having a Health Care Home, Ranked in Order of Frequency.

Rank	Barrier	Description (paraphrased from interviews)
1	Staffing challenges	Health care home model is human resource intensive; hard to recruit providers (there is more money in specialty care) and they aren't trained to work in this way or in community-based care.
2	Lack of insurance	These patients don't have insurance and overall revenues from patient care alone are neither sufficient nor configured to make the model work; unable to cover salaried educators, social workers, or community health care workers doing outreach; presently depending on grants.
3	Current system of reimbursement does not support a health care home	We know what the need is but aren't getting paid for that right now; medical care is for-profit; it's volume vs. value; you have to have enough volume to break even; change how providers are paid so they can focus on care and not get caught up in individual reimbursable moments; fee-for-service encourages sick visits instead of prevention; we are operating under a business model that doesn't support a health care home; isn't enough to cover what you have to pay for in

		staffing.
4	Necessary role changes are not accepted	Difficult to change the mindset that the physician handles everything; role of nursing is different at clinics; it’s hard for providers, especially older ones, to change; move from hierarchy where the doctor is the ultimate to a more an integrated team.
5	Technology	To be certified medical homes must have a solid technological base; electronic medical records are required, requiring people to use computers who don't like to.
6	Continuity	It’s difficult with migratory and transient patients; medical records - we don't have an electronic way to give a hospital or specialists our patient information if they are admitted; some health care plans won't open up their information systems to primary providers.
	Lack of places to refer patients	There are no behavioral health providers to refer to; there are not a lot of options available for referring undocumented patients; there is more need than there are places to refer people to.
8	Other	Lack of cultural competence; requires more internal communication; difficult to keep open appointments for established patients while still taking on new patients; new patients don’t have quick access to appointments.

Each community group member, navigator, and provider or administrator indicated along the scale where she/he felt health care for vulnerable adults currently falls (relative to the definition of the ideal patient-centered medical home). The median score for all groups combined was 39.5. Median scores for each group were as follows: community participants, 44%; navigators 40%: providers and administrators, 25%. The global scores from the linear scale for each group are shown in Figure 1.

Figure 1. Global Assessment Scores for Community Participants, Navigators, and Clinic Providers and Administrators.



PRINCIPAL FINDINGS

Finding #1: Having access to a health care home is viewed as desirable and should be a goal for vulnerable adult patients.

The clinical directors and administrators of the sites delivering services are familiar with the elements of the patient-centered medical home, accept their appropriateness, are actively trying to incorporate or build them into their respective clinical sites, and specifically agree that they are appropriate in the context of the vulnerable adult and Pathways.

This is not to say that many primary care sites have developed fully in the patient-centered medical home model. Several clinical directors and administrators noted structural barriers that are impeding the development toward fully providing these elements in the context of primary care. The median score of their global assessments in current attainment of the goal of reaching a full health care home was only 25%.

The definition of the patient-centered medical home has generally accepted elements that can be useful in assessing whether and how attainment of a health care home as a goal is being achieved. The comments and descriptions of health experiences described by community participants and navigators can be sorted and categorized readily under at least one of the elements within the definition of the health care home or under one of several barriers preventing attaining care in a health care home. The goal of a health care home was also positively received by them, with the elements of whole person care and patient-centered care of particular importance. Community members also recognized various responsibilities they would have as patients in a health care home.

Finding #2: For most vulnerable adult patients, the currently available primary care falls far short from being a health care home.

Community participants and navigators entered the focus groups largely unfamiliar with the idea of a health care home. Several accepted the definition as desirable, but for most part they focused on how this model isn't happening.

Participants' accounts of their own experiences engaging the care process and navigators' accounts of clients were more negative than positive across many elements of care. Global assessment scores referenced against full attainment of the health care home as defined averaged only 44% for community members and 40% for Navigators.

Multiple barriers for patients were described by focus group participants. Lack of money or insurance, and perceived stigmatization for being poor were frequently brought up in the discussions. Discrimination was described as a barrier to accessing care, notably racial discrimination, which was cited by Native American participants. Lack of legal documentation and limited abilities to communicate were issues presented barriers for immigrant patients, where a poor understanding about how to use the system and the lack of available and timely appointment slots were barriers shared by community members across population types.

Finding #3: Innovative health care home efforts provide opportunities for learning and replication.
Community participants and navigators cited certain specific clinical settings as being better able to address issues that relate to patient-centered care, care for the whole person, and coordinated care. These clinics are mission-driven and distinctive in existing specifically to provide services to vulnerable adults and families. At these sites, barriers to access and to the utilization of services do not exist, staff conscientiously anticipate clients' limitations and guide the patient through the clinical process. At one of them, an exit interview is conducted to assure that expectations at the end of a visit are clear. These clinics depend only minimally on fee for service payments.

Finding #4: Having an advocate may be essential for health care home success.
Of the many issues that separate the vulnerable adult from solid patient-centered care, there is a set that could be promptly addressed by providing an advocate inside the health care setting. (This parallels having a navigator or community health worker on the outside to help the vulnerable adult manage concurrent seriously adverse circumstances.) In the clinic setting, the vulnerable patient needs to be identified and the barriers to coordinated, patient-centered care assessed and addressed. Over and over, the stories cited instances reflecting the person's lack of comprehension of how to use the system, a lack of understanding the clinical process, and the caregiver's lack of receptivity to the realities of the person's living situation. The complications of co-occurring illnesses (including mental health problems) and the confounding overlay of suspicion and skepticism about the effectiveness of care, fear, frustration, or anger all come into play. At times the plans for follow up simply don't fit reality (e.g., a need for follow-up or referral, and the next available appointment is months away.) Many of these patients need an advocate at their side. The exit interview is an example of how this can work.

DISCUSSION AND CONCLUSIONS

Most reports about patient interaction with the health care system derive from samples of the patient population either inside the system or otherwise actively using the system. A distinguishing feature of the present investigation is that it samples people in the community. It specifically samples a population of vulnerable adults who might be expected to be handicapped in successful use of the health care system. It is not surprising then that such an investigation has yielded a lengthy recitation of problems. This group reported little connection to what we have characterized as a health care home (defined as having elements of patient-centered medical home). The examples of positive experiences tended to be fairly isolated or were cited either by participants able to pay for care in private clinical practices or by patients at the few facilities that specifically target immigrants or the homeless.

At the same time, there is consistent voice from clinicians and administrators that the model of the patient-centered medical home is appropriate and needed and that efforts should proceed to make the model available for these adults. They add that primary care needs more providers and staff to deliver a full model on the health care home. Further, the fee-for-service format creates pressure to prioritize the quick through-put of patients in a diagnose-and-treat pattern and detracts from patient-centered care, whole person care, and from the ability to take into account the patient's social and domestic contexts.

The community participants and navigators would like to have patient-centered medical homes. In this study, expectations for being able to obtain such care, however, were low.

On balance, in this investigation, the basic elements of the patient-centered medical home at present are more not working or not available than they are working and available for this sample of vulnerable adults. This applies particularly to access to care and to utilization of services, communication and continuity, patient-centered care, and whole-person care. Vulnerable adults face the consequences of organizational dysfunction and delays in scheduling. Doubts about the system being clinically effective were voiced in the focus groups, as were concerns about quality and safety.

Specific barriers evolve from not being able to pay for care, from perceptions of racism and classism, restrictive requirements for legal documentation, and not be able to navigate within the system.

Community participants commented on the inability to prioritize ongoing clinical care for chronic problems when either (1) they did not feel welcome or competent in navigating the care system or (2) they have to deal with other, competing issues in their lives. (Many such issues are targets for the Pathways model of intervention.) This perpetuates a cycle of returning to emergency rooms as acute, episodic needs for care arise. Indeed, patients related being told by clinic providers to use the emergency room should interim problems arise.

New Mexico has committed to Medicaid expansion to 138% of federal poverty level, and beginning January, 2014, the financial barriers to accessing medical services will be alleviated for many thousands of low income vulnerable adults in Bernalillo County. , While significant, this step will only illuminate the other barriers described by study participants, if attention is not given to identifying and supporting these newly-eligible patients in primary care settings. Of course, many County residents without legal documentation are left out of the opportunity for healthcare coverage altogether and will continue to struggle with the many barriers, including financial burden, to care.

RECOMMENDATIONS

1. The Pathways program objective for health care home attainment should be measured against the elements outlined for the patient-centered medical home.
2. Strategies for full implementation of the patient centered medical home model should be an institutional priority, and the strategies should consider the needs of vulnerable adults. Special financing is likely needed, perhaps coming from savings elsewhere in the health care system as additional revenue through Medicaid expansion is attained.
3. Especially at larger facilities, clinics should consider having a clinic-based navigator to assist patients who may experience difficulties managing the system. (Pathways

navigators are able to get patients to the hospital and often to specific appointments, but have little standing to navigate within the system.)

4. While the expansion of Medicaid will address current financial barriers to access, the County should assure funding for low-income residents who remain uncovered including those who lack documentation of legal immigrant status.
5. Clinics and facilities should evaluate the extent to which policies for provider reimbursement and other system incentives generate differentials of care that are based on ability collect payment for services.
6. Clinical services need to evaluate all aspects of the clinical encounter regarding a welcoming attitude, respect, and compassion.

LIMITATIONS

By introducing the elements of the patient-centered medical home into the focus groups and interviews, the responses may have been skewed toward expressing experiences that would be specific and, through comparison with suggested elements, critical of the present system. To counter this, the facilitator of the focus groups and provider interviewer began with open-ended requests for, respectively, descriptions of experiences in obtaining care and what would be needed to provide care. Furthermore, participants were encouraged to cite experiences that were positive in the sense of the system working as well negative experiences. Specific elements of the patient-centered medical care model were introduced only later and only then as probes in the context of whether they were applicable and/or appropriate.

When classifying a comment as to which one element of the patient-centered medical home may have applicability, the elements are not mutually exclusive. For example, the concept of coordinated care depends on most or all of the other elements: access, continuity, communication, organization, etc. This is such that we eliminated “coordinated” altogether from the analysis and chose instead to classify in terms of subordinate elements. Even then, it frequently required discussion to achieve agreement between the two readers to operationalize the definitions and resolve and finalize the assignment of content of the comments.

Comments were assigned to only one categorical element. Barriers constituted a set of categories in addition to the elements of the health care home. Assigning a comment to one of the barriers automatically resulted in an undercounted element from the definition of the health care home. For example a comment emphasizing lack of insurance as a reason for not accessing clinical care might have been classified as financial barrier or as a problem within the element of accessibility. In retrospect, the comment should have been tallied twice, once as a barrier and once with respect to the element. The authors limited their discussion of barriers to an ordinal ranking rather than as a percent distribution because of this problem. It is doubtful that the conclusions of the study and recommendations were materially affected, however.

The numbers of focus groups and total participants and numbers of provider interviews were necessarily limited by the resources. Increasing these numbers would likely have been rewarding and have assisted in gaining insights into factors that underlie the issues. It is unlikely such expansion would have changed the substance of the conclusions. While there was wide variety of experiences and commentary, there was remarkable uniformity in how the issues sorted across the different groups within this study. Nevertheless, some groups of vulnerable adults, for example, Blacks and Asians, were not represented, and their absence might have impacted the results.