



Lessons from the Health Care Innovation Awards: Productively Engaging Vulnerable Populations to Address Social Determinants of Health

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Abstract

Objectives: This paper examines productive interactions—a cornerstone of the Chronic Care Model—between health care providers and vulnerable populations with chronic illnesses and/or disabilities. **Methods:** We conducted qualitative analysis of 16 focus groups and 29 interviews with patients and/or caregivers and 195 interviews with program leadership and providers across 15 Health Care Innovation Awards that targeted vulnerable populations. We analyzed how awardees addressed health concerns and social determinants of health (SDOH), and identified key components of productive interactions. **Results:** Providers achieved productive interactions through four primary strategies: establishing trust and showing respect; solving problems; building accuracy in health information exchange; and sharing accountability and responsibility. While providers sought cooperation from patients and caregivers for medical goals, they often addressed SDOH priorities. **Discussion:** Strategies tailored to vulnerable populations can enable shared decision-making and effective self-care. A nonjudgmental engagement style, accurate information, and consistent communication are important for patient engagement.

Keywords

Social determinants of health; Chronic Care Model; productive interactions; vulnerable populations; health care innovation

Cover Page Footnote

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INTRODUCTION

Social disadvantage compounds clinical vulnerability among chronically ill patients with high clinical needs, leading to disparities in health care access and health outcomes (Adler et al., 2006). Vulnerable patients include those who experience chronic physical and/or mental illness exacerbated by at least one social determinant of health, such as housing instability, rural residence, and low education levels (Vulnerable populations, 2006). Disparities in health care quality persist between racial and ethnic minorities and their non-minority counterparts, as well as between individuals from low-income households compared with those with higher incomes (Adler et al., 2006; Bailey et al., 2017). Chronic illness rates are higher among vulnerable groups, and symptoms are often not controlled in accordance with medical guidelines. For instance, children of lower income families and those who are members of disadvantaged minority groups have higher rates of uncontrolled asthma, and lower-income adults with diabetes generally have higher blood sugar levels and more vascular complications than higher-income persons with diabetes (Beck et al., 2016; Grintsova, Maier, & Mielck, 2014).

Through the Health Care Innovation Awards (HCIA), the Center for Medicare and Medicaid Innovation (CMMI) funded programs throughout the United States that aimed to improve care and health outcomes while containing costs, particularly among those with the highest health care needs (Centers for Medicare & Medicaid Services [CMS], n.d.). Many HCIA awardees targeted enrollment for patients who were both clinically and socioeconomically vulnerable. Though systems-levels approaches are important for mediating social inequality and health disparities at a population level, productive interactions with providers can serve to improve health outcomes for individuals (Adler et al., 2016; Bradley & Taylor, 2013). The Chronic Care Model is an evidence-based model of care delivery for patients with chronic diseases that helps conceptually frame how many HCIA awardees organized their programs. The Chronic Care Model illustrates how health systems can use self-management support, delivery system designs, decision supports, and clinical information systems to inform and activate patients. Central to the Chronic Care Model are productive interactions between patients and their clinical practice teams (Wagner, 1998; James, 2013). There is evidence that productive interactions lead to improved health outcomes and care experiences for patients (Hibbard & Greene, 2013).

Productive interactions, which are said to “co-produce” care, are characterized by frequent and timely communication, problem solving, mutual respect, and a shared and accurate understanding of medical issues and care goals (Batalden et al., 2016). Productive interactions, therefore, require tailoring care to empower patients and meet their individual needs, making these types of interactions consistent with the overall concept of patient-centered care (Cramm & Nieboer, 2016). Productive interactions are characterized by a sense of provider rapport with patients, leading to feelings of mutual understanding, the development of shared goals, and trust (Kromme, Ahaus, Gans, & van de Wiel, 2016). This sense of rapport drives the level of collaboration achieved by patients and providers. Trusting relationships may lead patients to share sensitive information regarding personal or environmental circumstances, which can then allow collaborative problem solving around barriers to medication adherence or disease self-

management. Among chronically-ill patients, there is evidence that productive interactions are associated with both higher quality of care delivery and patients' greater feeling of well-being (Cramm & Nieboer, 2014; Cramm & Nieboer, 2015b).

Some HCIA programs designed to meet the needs of vulnerable patients with high costs and high needs demonstrated substantial improvements in outcomes and reductions in costs ([Authors], 2016; [Authors], 2017). This paper examines strategies and approaches HCIA programs employed to engage these populations, particularly addressing how facilitating productive interactions between providers and patients worked to engage vulnerable patients and address social determinants of health and health outcomes (Bernabeo & Holmboe, 2013; Blumenthal & Abrams, 2015).

Disenfranchisement from the Health Establishment

Productive interactions may lead individuals with chronic illnesses to engage in better self-management, such as monitoring their symptoms, making lifestyle changes, adhering to medication regimens, and attending medical appointments (Pearson, Mattke, Shaw, Ridgely, & Wiseman, 2007). However, people often prioritize immediate survival needs such as social determinants of health like food and housing over managing long-term health issues (Maslow, 1954). Adults with lower family incomes more often report delaying needed care than those with higher incomes (Schiefelbein, Olson, & Moxham, 2014), and typically face serious barriers to self-care, such as environmental contamination in their housing (Cushing, Morello-Frosch, Wander, & Pastor, 2015), lack of transportation (Syed, Gerber, & Sharp, 2013), or limited access to stores with medicines and healthy food (Weaver, Lemonde, Payman, & Goodman, 2014; Qato et al., 2014). Addressing these systems-level issues is an important prerequisite for engaging vulnerable groups in care (Remien et al., 2015). Despite the importance of mitigating barriers, providers may lack the ability to address social determinants of health for vulnerable groups because they are socially disconnected from these patients; do not collect or consider the demographic data necessary for addressing these issues; or lack a substantive understanding of how social determinants affect their patients' health status. This may result in inappropriate care plans to which patients cannot or will not adhere (Bloch, Rozmovits, & Giambrone, 2011). Patient-provider communication fundamentally requires time (Bernabeo & Holmboe, 2013), but payment mechanisms typically reward volume over value, keeping face time with providers short.

Both providers and patients may lack understanding of medically relevant details. Providers do not always recognize challenges that vulnerable patients face, and although socially vulnerable patients may want to share in health care decision making, they may lack adequate information and health literacy, causing them to feel as though they are "outsiders" to the decision-making process (Ebert, Bellchambers, Ferguson, & Browne, 2014). Low health literacy can create perceived "power differentials" (Castaneda-Guarderas et al., 2016) that limit patients' ability to communicate effectively with providers or to navigate the health care system, leading to poorer chronic disease management (Ursan et al., 2016; White et al., 2016). Poor patient-provider communication is associated with lower levels of trust and respect between patients and providers, particularly among racial and ethnic minorities, lower-income patients (Calo, Ortiz, Colon-Lopez, Krasny, & Tortolero-Luna, 2014), and individuals with lower levels of education (Richardson, Allen, Xiao, & Vallone, 2012) and health literacy (Castaneda-Guarderas et al., 2016; White et al., 2016; Samuels-Kalow, Hardy, Rhodes, & Mollen, 2016).

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Mistrust among vulnerable patients may derive from the perception that providers do not share their goals or perspectives (Powell, Doty, Casten, Rovner, & Rising, 2016). Some health care providers blame patients' health and social challenges on patients' personal failings rather than systemic factors (Bloch et al., 2011), use judgmental or stigmatizing language (Carroll, 2019), or verbally dominate interactions (Giambra, Haas, Britto, & Lipstein, 2018), further jeopardizing patient trust. Medical mistrust is particularly acute among racial and ethnic minorities who face a long history of unethical research and exploitation (Armstrong et al., 2013). Lack of trust and respect is connected to challenges with shared decision making and shared responsibility, key components of productive interactions. Patients' level of trust in their providers influences their willingness to engage in shared decision making (Powell et al., 2016), but providers are often less likely to be responsive (Levinson et al., 2008) and more likely to be verbally dominant when speaking with patients who are members of minority racial-ethnic groups (Johnson, Roter, Powe, & Cooper, 2004). Minority patients are less likely than White patients to report that their providers shared treatment decision rationales based on clinical experience and scientific research (Lin & Kressin, 2015).

Vulnerable patients may require a higher level of engagement and motivation from their providers than the population at large. However, many care delivery trends favor patients who have a greater capacity for care coproduction over those inhibited by psychosocial barriers (Shim, 2010), creating a self-perpetuating cycle in which the better off reap benefits from the health system because it is designed for people like them. Because patient engagement is lower among vulnerable populations, efforts to improve patient engagement have the potential to reduce health disparities (Chen, Mullins, Novak, & Thomas, 2016).

METHODS

The Center for Medicare and Medicaid Innovation awarded the first round of HCIA in 2012. Under contract with CMMI, [research organization masked for blind review] led two independent mixed methods evaluation projects that included 42 of the 108 awards. Detailed results on these evaluations are available in the programs' evaluation reports ([Authors], 2016; [Authors], 2017). This paper examines the findings on patient engagement for 15 of the HCIA programs that targeted patients who were members of vulnerable populations and who were living with chronic illnesses or disabilities (Paradise, 2015).

Study Design and Sample

This paper primarily presents analysis of qualitative (interviews, focus groups, and observations from in-person and virtual site visits) data, and offers a snapshot of quantitative claims analysis as context for the overall performance of the HCIA programs. To identify which awardees served vulnerable populations, we included awardees in this study if (1) 50% or more of an awardee's participants identified as non-White and/or (2) if the majority of an awardee's participants were dual-eligible or insured by Medicaid. Our final sample includes fifteen awardees that met at least one of these criteria. We note that we identified the awardee subset using insurance status as a proxy for low-income children, disabled, and elderly populations because Medicaid and the Children's Health Insurance Program (CHIP) are means-tested public benefits that primarily serve these populations. Medicaid expansion in some states also increased enrollment of low-income, non-elderly adults in this program (Paradise, 2015). After identifying the awardee sample,

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we analyzed qualitative data on the extent and manner through which the programs were able to engage the intended populations. The majority of the awardees in this study realized reductions in utilization, cost savings, or both. Utilization and cost data, provided here as context for the qualitative analysis, were assessed using claims.

Data Collection

We collected qualitative data from April 2014 to June 2015. This analysis includes data from 16 focus groups; 29 interviews with participants and/or caregivers; and 195 interviews with program leadership, staff, and providers across 15 awardees. Our qualitative data for patients sampled included perspectives from approximately equal numbers of male and female participants; the majority of caregivers were female. All focus groups were conducted in-person during site visits. Individual interviews were conducted either in-person or by phone. Documents reviewed for analysis included quarterly program reports to CMS, related technical reports and peer-reviewed publications, and administrative and training documentation shared by the programs.

Data Analysis

For the qualitative analysis, we prepared transcripts of individual and focus group interviews based on verbatim notes and interview recordings (Onwuegbuzie, Dickinson, & Leech, 2009). For this particular analysis, we used NVivo software (version 10, QSR International) to code for key components of productive interactions as identified in the literature and through the interviews themselves (Cramm & Nieboer, 2015a). Codes were: accuracy, frequency, timeliness, trust, respect, problem solving, shared goals, and shared responsibility/accountability. Inter-rater reliability was assessed through consensus-building discussions among coders and subject matter experts, and reliability calculations and spot checks helped assure quality of analyses (Garrison, Cleveland-Innes, Koole, & Kappelman, 2006; Bradley, Curry, & Devers, 2007). Coding allowed for thematic analysis of productive interactions, both among transcripts of interviews from the same awardee and across awardees, revealing commonalities in the core components of such interactions regardless of the target health condition or patient population. Complete details on our methods for qualitative and quantitative analysis used in our evaluations of the HCIA, including the claims and difference-in-difference analysis presented in this paper, can be found in the technical appendices to our second and third annual HCIA evaluation reports to CMMI ([Authors], 2016; [Authors], 2017).

RESULTS

Awardees implemented various interventions to improve engagement, patient satisfaction, and health outcomes and to reduce utilization and expenditures among a diversity of awardees and populations. We examined the populations served, the interventions implemented, and how interventions affected the interactions patients and caregivers had with individuals working for the health systems (broadly referred to as providers). In this paper, we present qualitative findings on the four dominant components of productive interactions that emerged from the data: 1) trust/respect; 2) problem solving; 3) the accurate exchange of information; and 4) shared responsibility. Improving communication and creating productive interactions were often associated with reduced costs and utilization of hospitals among participants.

Description of Interventions

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Awardees targeted two primary categories of patients: (1) those with a chronic illness, such as diabetes, pediatric asthma, or end stage renal disease, or (2) those with complex health conditions caused by multiple chronic conditions or conditions complicated by intellectual or developmental disabilities (IDDs). Awardees were largely academic medical centers or centers specializing in patients with IDDs. Most were also located in low income areas and served vulnerable populations by design.

In keeping with the Chronic Care Model, awardees used an array of interrelated strategies to improve patient outcomes. Strategies largely focused on improving care coordination within and across health systems and providing self-management support. Some also focused on delivery system designs, decision supports, clinical information systems, and enhanced access to community resources. Enabling productive communications between patients and care teams was central to awardee efforts under HCIA.

To cultivate productive interactions, the majority of programs leveraged clinicians and frontline staff with past experience with the target population. In many cases, programs hired individuals whose backgrounds were similar to the program's patients, offered or referred patients to social resources, and dedicated resources to developing linguistically and culturally appropriate patient education materials. Staff were both clinical (e.g., physician's assistants, nurse practitioners, and medical assistants) and non-clinical (e.g., social workers, certified health educators, and lay community health workers). As noted previously, all are referred to as providers throughout this paper.

All awardees, regardless of patient population or health conditions targeted, employed some form of care coordination services. In most cases, care coordinators were individuals within health systems who helped patients and caregivers navigate the health care system and address social determinants of health. Often trained for specific programs, care coordinators worked to achieve productive interactions through interpersonal, one-on-one interventions with patients.

Select frontline staff were sometimes instrumental in facilitating communication between patients and/or caregivers and other members of the care team, but awardee key informants emphasized the need to improve communication and interactions with all health care staff regardless of their credentials or role. As our analytical focus is on how vulnerable populations interact with individuals working in and for medical establishments in general, we have not differentiated analysis of productive interactions by the type of provider or their credentials.

Table 1 provides an overview of HCIA awardees included in our analysis, offering descriptions of program activities and diseases targeted. These include whether the awardee served predominantly racial/ethnic minorities, Medicaid, and/or Medicaid and Medicare populations, and whether it achieved a significant reduction in one or more key outcome measures (impacts) related to health care utilization (i.e., emergency department (ED) visits, readmissions, or hospitalizations) or cost of care.

The quantitative findings serve as context for the qualitative analysis. Particular demographic characteristics or findings are identified with a dot. We found that five of the awardees significantly reduced both utilization and costs among their target populations. Five more significantly reduced utilization measures, and one only costs. The four remaining programs either did not achieve any reductions in costs or utilization, or the reduction was not found to be statistically significant relative to a comparison group.

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Following Table 1, we provide an in-depth look at findings on the central feature of the Chronic Care Model—productive interactions between providers and patients and/or caregivers—that support its importance among awardees working with vulnerable populations.

Table 1: Overview of HCIA awardees targeting vulnerable populations, including claims analysis of impact

Organization/ State(s)	Target Population				Intervention Description	Evidence of Impact*	
	Targeted Condition/ Disease	Racial/ Ethnic Minority	Medicaid	Medicare		Reduced Cost	Reduced Utilization
Providence Portland Medical Center (PPMC)/ OR	Multiple Chronic Conditions	•	•	•	Aimed to coordinate care for adult high-risk and high-acuity Medicaid and dually eligible Medicare and Medicaid beneficiaries through seven distinct hospital- and community-based interventions, including an ED diversion program for high-utilizer beneficiaries with non-acute needs.	•	•
Sutter Health Corporation (Sutter)/ CA	Multiple Chronic Condition, End of Life			•	Offered care coordination among hospital, home health, physician’s office, and hospice care, delivered by interdisciplinary teams of nurses and social workers, for seriously ill patients believed to be within the last 12 months of life.	•	•
University Emergency Medical Services (UEMS)/ NY	Multiple Chronic Conditions	•	•		Community health workers (CHWs) recruit participants among non-urgent hospital ED patients and primary care settings, providing weekly, one-on-one coaching to facilitate patient-directed goal-setting, navigation and referrals to community supports, and connection to primary care.	•	•
University of New Mexico (UNM)/ NM	Multiple Chronic Conditions		•		Expanded on the Project ECHO model to deliver weekly clinic and home-based care, linking a team of specialists at the University of New Mexico with multidisciplinary outpatient intensivist teams (OITs) at six rural sites around the state.	•	•
University of Texas Health Sciences Center (UT Houston)/ TX	Multiple Chronic Conditions	•	•		Dedicated outpatient services and around-the-clock phone access for medically complex children enrolled in Medicaid, including family caregiver education, social services referrals, assistance with durable medical equipment, and home visits to assess housing conditions.	•	•
Courage Kenny Rehabilitation Institute (CKRI)/ MN	Physical Disabilities		•	•	A medical home that co-locates primary and specialty care, makes referrals for community service and supports, and offers classes by a nurse care manager and peer.	•	
Developmental Disabilities Health	Intellectual/ Developmental Disabilities		•	•	Expanded its health home model to six clinical sites with primary care, mental health, and specialty medical service teams.		•

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Organization/ State(s)	Target Population				Intervention Description	Evidence of Impact*	
	Targeted Condition/ Disease	Racial/ Ethnic Minority	Medicaid	Medicare		Reduced Cost	Reduced Utilization
Services (DDHS)/ NJ, NY							
George Washington University (GWU)/ Washington D.C	End Stage Renal Disease	•	•	•	Provided a remote telemonitoring program for patients through nurses at 10 local, private clinics specializing in renal care.		•
Le Bonheur Community Health and Well-Being (Le Bonheur)/ TN	Pediatric Asthma	•	•		Offered comprehensive asthma care management, education, and social support through specialist-led clinical care teams and home visits by CHWs.		•
LifeLong Medical Care (LifeLong)/ CA	Multiple Chronic Conditions	•	•	•	Offered clinic-based care coordination and client engagement to high-risk adults through home visits, peer-coaching and independent living (IL) workshops.		•
Nemours Children’s Health System of Nemours Foundation (Nemours)/ DE	Pediatric Asthma	•	•		Utilized CHWs in patient centered medical homes (PCMHs) to improve asthma care management for pediatric patients on their asthma registry and address environmental triggers of children living in the communities surrounding the three participating practices.		•
FirstVitals Health and Wellness, Inc. (FirstVitals)/ HI	Diabetes	•	•		Diabetes management telemonitoring and screening program that incorporated remote transmission of data to care coordinators in community health centers in real time through participants’ use of electronic tablets, wireless glucometers, and blood pressure cuffs.		
Health Resources in Action, Inc (HRiA)/ CT, VT, MA, RI	Pediatric Asthma	•	•		CHWs and certified asthma educators (AE-Cs) made home visits to provide education and subsequent reinforcement in addition to environmental assessments and cleaning supplies for families of children with asthma.		
Johns Hopkins University School of Nursing (JHUSON)/ MD	Multiple Chronic Conditions	•	•	•	An occupational therapist and RN care manager conducted home visits over 16 weeks, collaborating with the client to identify one or more goals to improve functioning and to take steps toward achieving the goal(s).		

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Organization/ State(s)	Target Population				Intervention Description	Evidence of Impact*	
	Targeted Condition/ Disease	Racial/ Ethnic Minority	Medicaid	Medicare		Reduced Cost	Reduced Utilization
University of Rhode Island (URI)/ RI	Intellectual/ Developmental Disabilities		•	•	Offered clinic-, home-, and community-based access to primary care, integrated with patient empowerment, social services referrals, and employment services for adults living with IDD.		

Deconstructing Productive Interactions

Providers among the 15 HCIA awardees were able to achieve productive interactions with patients and caregivers through four primary tactics: establishing trust and showing respect; solving problems; building accuracy in the exchange of health information; and sharing accountability and responsibility with patients and caregivers. The following findings consider each of these four tactics and emphasize interrelationships among them.

Trust and Respect

Coded findings on trust and respect include observations of challenges in establishing trust between patients and their care team members; identification of respectful approaches toward specific patient populations; and specific incidents between patients and providers where trust or respect were perceived and reported, either explicitly or implicitly.

Overall, providers recognized that the burden of establishing trust with patients and caregivers fell largely on them. Rather than judge their vulnerable patients or “blame the victim,” providers in the sample expected to be met with skepticism and mistrust from the vulnerable populations that they served. By offering assistance respectfully to patients and caregivers, providers sought to earn trust over time. Awardees focused on specific populations or those with specific disease conditions, such as childhood asthma, and some of the ways providers overcame trust issues were population-specific. The following examples suggest the challenges to achieving trust among specific awardees and general strategies to facilitate trusting relationships.

Low Income/Multiple Chronic Conditions

Providence Portland Medical Center’s (PPMC’s) program worked to transform the health systems’ perceptions of their target population from “high utilizers” to vulnerable populations. Rather than viewing patients through the lens of a decontextualized outcome measure (utilization), the program considered the reasons for “undesirable” utilization patterns, creating a patient-centric lens. The health system integrated a trauma-informed approach across multiple interventions using six key principles to address trauma: safety; trustworthiness and transparency; peer support; collaboration and mutuality; empowerment, voice, and choice; and cultural, historical, and gender issues (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014). The program offered staff formal training on the trauma-informed approach and other topics such as motivational interviewing. They also created a staff position called a Health Resiliency Specialist that emphasized the program’s intent to help empower patients. Two PPMC providers described a fundamental shift in thinking about their patients within their health system:

“We’re walking into situations when there is a lot of reactivity in medical system around our people – drug-seekers, personality disorder, lots of negativity...To help people move forward, we have to be able to address that. People have major traumas in their life that affect interpersonal skills and how they deal with pain and stress, work, and having more money. With TIC, there is a reason behind everything.”

“These are people who have had very unsuccessful lives, so it’s really about a trauma recovery program. These are not really high-utilizers; rather, they are being forced into high utilization since the medical system does not know what

people are really going through. This is also a population that has learned not to trust anyone in the world, so how do you help re-socialize them and give them the confidence to engage with the system?"

To overcome mistrust, PPMC providers prioritized compassion and let patients know that providers were available when the patients were ready. Providers were instructed not to rush patients through their ED diversion program. Key informants also felt that the voluntary nature of their programs helped build trust; patients were seen as being in a "position of power" by choosing to join the program as opposed to submitting to mandates related to criminal justice and public assistance systems. When trust was established, providers sometimes became surrogate families for patients who were alienated from their families as a result of addiction and associated behaviors. With this level of trust, PPMC providers could help vulnerable patients better navigate the health system and self-manage their health.

Asthmatic Children and their Parents

Many parents and caregivers of asthmatic children felt that medical providers doubted or judged their parenting skills and did not believe parents' accounts of care they provided when their children had asthma attacks. Parents dreaded going to the emergency room and to medical appointments, in part because of implied and explicit accusations that they did not care for their children properly.

Many parents enrolled in the HCIA asthma programs initially avoided the medical system. Though parents said they were skeptical at first, they started to see results from the programs or started to understand more about the cause of their child's asthma. As a result, they began to trust their providers more and bidirectional communication between providers and parents improved. One mother explained that her first encounters with an asthma program came after a visit from a truancy officer and child protective services:

"That day I was just down, and I really didn't want to hear nothing [a provider] was trying to talk to me about... the same day I met [the specialist], and she explained to me why [my daughter] was having so many asthma attacks was because of the pollen. And once we got her on the right medication and actually got me used to the shampoo and stuff in her hair, we've only had two outbreaks in the past year." (Le Bonheur caregiver)

Caregivers reported that their asthmatic children also experienced systemic mistrust, particularly at school. Parents claimed schools accused their children of misbehavior when the children needed to leave class to get medication and believed that harsh treatment from teachers sometimes triggered attacks. Many reported conflicts with their children's schools regarding such treatment. Asthma programs earned parents' trust by acting as liaisons between the families, clinics, and schools. Program staff often educated personnel at schools and other institutions about patient care plans and appropriate asthma treatment. Parents appreciated this support, particularly since it enabled their children to receive appropriate treatment and reduce school absences.

Older Adults

Older adults who enrolled in HCIA programs had often been unable to obtain appropriate diagnoses or effective treatment for their health conditions and had become wary of the health care system. Many reported that they found providers to be condescending. Lifelong provided care coordination and independent living specialists to help patients navigate complex medical systems. While these services did not always directly affect patients' interactions with their providers, they did provide a trusted interface with the health system.

One participant of this program had been seeking treatment for undiagnosed health conditions for ten years. He said he was reluctant to speak with the care coordinator, and at first he had the coordinator speak with his wife. He ultimately came to rely on his care coordinator and trust her to help him get referrals and intervene when he had issues with doctors. He explained,

“Talking with [the care coordinator], she made things start clicking... She keeps you informed, and updated about what she is doing. You are not lost at all... She lets you know that you are still a human being. Because sometimes they make you feel like you are a dollar sign... Her number is in my cell, no matter what the issue is. You can't leave a message for your doctor, but I can for her. If she leaves [the program], I am leaving.” (Lifelong patient)

Through working with his care coordinator, the patient felt that his care improved and that he received faster and more useful responses from doctors.

Lifelong also worked to encourage older adults to develop more “self-trust” so that they could advocate for themselves with doctors. One peer health coach found that seniors start to “lose bits and pieces of [themselves],” and lose their confidence in speaking about their needs with health professionals. The health coach worked with patients to document their issues so that they would be more prepared and self-confident when speaking with their providers. Increased “self-knowledge” helped patients make decisions and “push through to get what [patients] want.”

Patients with Diabetes

Among patients with diabetes, several explained that harsh or dismissive attitudes of health care providers discouraged them from self-monitoring or seeking to improve their health. Providers who were considered “gruff” put patients in a position where they avoided confrontation by saying they checked their blood sugars levels when they did not or saying they were feeling fine when they were not. One patient recalled insulting encounters: “I've had a lot of experiences with physicians [who] just look at me and say ‘you're fat’ and expect me to crawl under a bush and die.” FirstVitals offered diabetic patients home monitoring equipment that shared results with providers, and one patient said his FirstVitals providers were “caring professionals that made you feel like they give a damn about your medical condition.” The remote telemonitoring equipment made him feel he was “a vital part” of his own health care success.

Patients with Disabilities

Among patients with intellectual or developmental disabilities, mistrust of the medical system prevented many from initiating care at any medical facility. A provider who served disabled children recognized that many patients had histories of “degrading and negative experiences” in health care settings (DDHS intervention). Whether such individuals were highly functioning and independent or not, a history of negative experiences posed a challenge to patient-directed care,

DDHS providers' goal in serving this population. Providers noted the importance of subtlety and individualized approaches in establishing trust. A provider at the University of Rhode Island who served this population explained:

“The most effective part of my job is in the little, small incremental contacts. Maybe making eye contact for the first time, and then say a name, or maybe wanting to hold my hand, and eventually that person will begin to tell me about themselves. It is trust building, but that is a big issue. There are very few aspects of the job or the interactions that a person can take for granted or quantify. It is very qualitative compared to empirical. To have any kind of relationship with participants we have to go with what they are willing to give and that really varies and is the important part of the job.” (University of Rhode Island provider)

Respecting patients' wishes by allowing patients to set the pace of their interactions with health care providers was foundational to more broadly demonstrating interest in the whole patient, such as “their goals, [and] their social life,” as articulated by one provider.

Across the various programs in this analysis, individuals repeated a refrain that providing judgment-free care and enabling patients and caregivers to drive the agenda at their own pace could build trust so that patients and caregivers could productively engage with providers to address their health issues.

Problem Solving

Understanding patients' problems and their effects on both patients and caregivers health helped providers address health issues. Providers efforts to listen, understand, and address basic issues helped build trust with patients and created a virtuous cycle in which trust led patients to further work cooperatively with providers. Providers tried to address all urgent needs raised by patients and their families—they not only addressed typical barriers, such as transportation, insurance paperwork, and filling prescriptions, but also tried to probe on what could be causing health problems, such as changes in a patient's diet or sleep patterns or inappropriate dosages of medication, and worked to address those issues.

At Courage Kenny Rehabilitation Institute (CKRI), patients with traumatic brain injuries had difficulty speaking with providers, let alone organizing their care and lives. The providers assisted with daily living needs as well as health. One woman explained:

“[My caseworker] finds a lot of things for me, free things to do, low cost dog food, PCs for people, fairs for all groceries, a referral to a garage that would get my car fixed. One day we went down to the social security office and five days later I got \$2782 in back pay. And I didn't know that I was missing it and I can't call them because I don't understand what they're saying. It's so intimidating there. And you do have to ask but they do bring it up and have resources like crazy” (CKRI patient)

At PPMC, program staff assisted with a wide range of issues in order to prevent ED overuse. One provider explained:

“I’ve done everything... a patient was primarily stressed about cat’s eating. I picked up cat food, chatted, had some coffee, and met her neighbors. We deescalated her, and diverted her from the hospital. It’s different for every person, but meeting them where they’re at. We sometimes provide a hotel for the homeless if it’s hard to get them appointments. We try to wrap support around their needs.”
(PPMC provider)

Case managers in programs for pediatric asthma patients sought to recognize patients’ and families’ immediate and urgent needs, and when necessary, made service referrals before addressing asthma. One provider explained:

“You know, if we come into a family and housing is their most important priority, we need to talk to them about that... We need to say ‘you know, tell me what the problem is.’ I’ll write the problem down, and [say] ‘you know what, I’m going to call the social service... and we’ll see what we can do about this, okay? Is there anything else you want to tell me...? Okay, now let’s get to why I came here.’ You know, you can’t push aside what their most important line item is, because you won’t get anywhere and you’ll never get back in the door.” (HRiA Asthma Educator)

Similarly, another asthma program found economic problems eclipsed individual health concerns. Consistent with Maslow’s hierarchy of needs, program staff observed that until needs for food and shelter (level one) and safety (level two) were met, patients did not have the psychological resources to address their health unless they faced a crisis (1954). A provider explained:

“...It’s not that [families] don’t want to adhere to what they need to do for their child...[It’s just that] ‘right now I have a rent problem. Right now I have a food problem’. And they’re not neglecting their child, it’s that they have to take care of what’s going on right now.” (Nemours care coordinator)

Addressing acute basic needs freed family resources to manage a child’s asthma.

Accurate Exchange of Information

Awardees worked to improve the accuracy of information exchanges between patients and caregivers, but improvement depended on first developing trust between patients and their providers. Strategies to improve both accuracy and trust included educating patients on medical and health topics, educating providers about social and environmental conditions that affected patients’ health and health-seeking behaviors, employing a culturally competent workforce, and trying new technologies.

In terms of content, patient education largely focused on self-management related to medications, diet, lifestyle issues such as exercise, environmental triggers, and self-monitoring. Most programs offered educational materials in multiple languages and/or hired at least one bilingual staff member to communicate accurately with non-English speaking participants. Below,

we describe the specific techniques and education awardees used to communicate across different patient and caregiver populations.

Awardees working with older adults focused on building accuracy around medications, including reconciling medications and assuring they were taken appropriately. Most awardees helped organize patients' medications and were accessible in case patients had any questions or needed support in taking them.

Parents of children with complex health conditions at UT Houston were taught how to use and adjust home medical equipment, such as ventilators, to meet their child's immediate needs. Understanding how to make the adjustments independently relieved anxiety parents experienced in caring for children with severe disabilities. For pediatric asthma patients, awardees spent considerable time educating caregivers on how to use inhalers, the dosage of medicines, and when to use emergency medications. Program staff worked to convince caregivers that a daily steroid was safer than a high-dose rescue medication received in the emergency room, that daily steroids should be taken as prescribed, and that children themselves could help identify the onset of asthma attacks and manage the administration of their doses. One caregiver said:

“The medicine that he takes is every day medicine. The medication, I didn't know that he was supposed to be taking it like that. You know, I'm like, 'he's fine so he doesn't have to take it.' I didn't know he was supposed to take it...Then when I joined CHAMPs, they gave me a folder, they gave me instructions, gave me a calendar, told me all kinds of ways to get it right. And [they] even gave my son a watch and it goes off every time it's time for him to take his medicine, no matter where he's at. So it has really, really, really helped.” (Le Bonheur caregiver)

Providers also focused on the way homes should be cleaned and emphasized vacuuming regularly and using cleaning methods that were least noxious to asthma patients.

In terms of communication with patients and caregivers, many awardees used intermediary providers, such as peer educators, community health workers, or home visitation staff, to gather more accurate information about patient's lives and health conditions, and to provide health education and support. Many of these individuals were lay health workers hired from the communities they served and brought specific cultural knowledge related to subpopulations and/or had disease or condition-related personal experiences that informed their work. Intermediary providers gained trust to access patients' homes—some assessed patient safety in older adults' homes, asthma triggers of asthmatic patients, and general adherence to medical regimes prescribed by providers. Culturally competent lay health workers in particular could seek more accurate information about patients' lives because of cultural knowledge, which helped them identify why patients followed medical advice or why they may not and how to approach patients and caregivers in a culturally-informed way to increase adherence to treatments and medical advice. Such staff also helped bridge the communication and cultural gap between other providers and patients. Often what providers thought of as plain language was not understood by their patients. As one specialist explained: “there's just such a barrier between me and this population. If you're going to be successful, white coats and specialists aren't going to solve the problem alone.”

Technology also served as an intermediary between patients and providers that improved accuracy in patient/provider communication. Three awardees offered telemonitoring to promote patients' health self-management and to communicate potential health problems with providers in real time to varying degrees of success. For example, George Washington University's (GWU) home-based peritoneal dialysis patients found mixed value in telemonitoring since they were already required to take their blood pressure and weight daily, and intervention staff had difficulty integrating the patient monitoring data into their workflows. FirstVitals reported that telemonitoring technology improved communication between patients and their providers and encouraged self-monitoring of blood sugars and blood pressure among diabetes patients. Many patients in that intervention praised the program and technology for keeping them better informed and better connected to their providers. Most reported that the technology helped them check their blood sugar and blood pressure more regularly, and that, coupled with the education from their providers and the genuine interest providers expressed in their health, the technology motivated them to dedicate more effort to self-management. One person explained how the education and technology created a "circle" of communication:

"[FirstVitals] will alert us to make sure we know what we're doing, and it's better education also for the team to see how they can better the supplies or the medication that people take for diabetes... You [providers] are doing you guys' job by giving us the medicine, trying to find out what causes diabetes, period. And we're the ones that feed you the information that says, 'hey, if I do this with my diet, watch what I eat, not too much sweets not too much carbs,' then we're doing our part on our side. And it's almost like a cycle...instead of, 'ok, I'm guessing this is the number, no, ok, maybe that's the wrong guess.' So yeah, the education part is really important." (FirstVitals patient)

Finally, awardees invested in efforts to improve the accuracy of the information providers exchanged among themselves. They strove to share care plans between primary and specialty care providers, convene multi-disciplinary care teams, and utilize case management software and electronic medical records to make sure providers within a patients' health care network had up-to-date information at the same time.

Shared Responsibility

Providers and patients/caregivers felt mutually responsible for aspects of communication, care, and treatment. Many patients acknowledged responsibility for performing self-management activities, and providers described their reliance on patients' efforts to manage their own health.

In general, awardees' focus on trusting relationships, problem solving, and improving accuracy helped create shared responsibility. Many awardees were successful in motivating patients to engage in their own health care, and patients were quick to say they did so because they felt that someone cared and because their providers were supportive. One older adult explained:

"I used to go to the hospital all the time for my heart and pacemaker and knee and back pain...I used to call [an] ambulance, and I get scared when I have breathing problem because my heart stopped three years ago. Since I have AIM, the nurses

and social worker that come visit me are excellent and they communicate to the doctor and the doctor answers their calls. I have been happy with that, and for the last year I have not gone to the hospital. I manage my problem. I am getting stronger. I am good at following doctors' orders. I feel protected and I feel good. I am saving money to the system by not going to the hospital. I recommend AIM to many people.” (Sutter patient)

Many patients and caregivers interviewed for this study described themselves as part of a team-based approach to care with providers. One caregiver of an asthmatic patient said:

“So if I’m doing something incorrectly, let me know, because I don’t know. And not to sound sarcastic, but I’m not a nurse. So nurses, respiratory therapists, the doctors – you know, it’s a whole team, it’s a whole team effort. Everyone could assist me with helping [my daughter].” (Le Bonheur caregiver)

Many health care providers also emphasized the importance of listening to their patients. At UT Houston, parents were encouraged to trust their own assessments of their medically fragile children, and providers were encouraged to listen. One provider explained:

“It’s important to understand the families, the pain they have, and the stress they are under. These situations are difficult, parents can be in a bad mood sometimes but we still need to listen to them. Most of the time the parent is right; if they think their kid is sick then they’re sick. This is a cooperative effort with the families” (UT Houston provider)

Many patients and caregivers interviewed appreciated the efforts of their providers, but also emphasized their own responsibility in their health care. At a CKRI focus group, one participant said:

“I think it sounds like we all have good [Independent Living Skills] workers. And there’s a difference between living and existing. She moved me from existing to living, and she doesn’t let me slack off.” (CKRI patient)

DISCUSSION

Fifteen HCIA interventions with diverse approaches and objectives employed multiple strategies toward a shared goal, to improve interactions with the vulnerable populations they served. Collectively, they built trust and improved shared decision making between patients and providers. While providers still sought to gain cooperation from patients for medically oriented goals, they recognized that vulnerable populations often had priorities around social determinants that took precedence, such as food or housing security. In contrast to labeling patients as non-compliant when they do not follow top-down medical advice, as is common, the awardees used strategies to improve communication, such as motivational interviewing, home visits, and enhanced access to care that could encourage and better enable patients to meaningfully share in

health care decision making and implement effective self-care. Our findings build on a developing body of work that shows that attitudes toward health care, trust, and good communication are crucial components of patient engagement (Kromme et al., 2016; Remien et al., 2015).

Though the awardees' efforts to cultivate productive interactions were part of a range of efforts to improve quality and access to care, the majority of our cases with productive interactions as a central component (11 of 15 HCIA interventions) achieved quantitatively measurable impacts on cost, utilization, and/or quality of care. However, the fact that we identified evidence of productive interactions even among those who did not reduce costs or utilization relative to comparison groups indicates that such interactions may not be sufficient to achieve outcomes. Awardees utilized multi-dimensional approaches, and those that were able to reduce costs and utilization among participants may have had other aspects of their interventions, or a particular combination or degree of implementation of intervention components, which drove outcomes. While studies have found that some providers think that productive interactions are spontaneous and thus cannot be taught (Kromme et al., 2016), there is evidence that many providers simply lack the skills needed to engage productively and that these skills can be learned through appropriate training (Moreo, Greene, & Sapir, 2016). However, providers serving high-risk populations may be more likely to be associated with resource-scarce institutions, giving them less time to engage with patients and fewer resources for changing practice, thus exacerbating health disparities (Moreo et al., 2016).

Providers have the capacity to productively engage with patients in order to empower them, but the literature notes research gaps specifically regarding ways to simultaneously improve patient trust and shared decision making among patients who are members of minority groups (Shim, 2010). There are also gaps in evidence regarding the relationship between interventions that focus on patient engagement and demonstrated cost savings (James, 2013; Hibbard & Greene, 2013). Our findings address these gaps and suggest that specific tactics for achieving productive interactions as a feature of patient engagement may contribute to reductions in cost and utilization as accompanied by improved care and patient experiences.

As payment reform continues to focus on population health management, health systems are increasingly dedicating resources to managing and engaging the highest cost and highest need patients. This study provides examples of intimate care coordination approaches that diverse interventions have used successfully to address the needs of vulnerable populations. Strategies tailored to the needs of specific populations and individuals can enable outreach to groups who have historically been reluctant or unable to engage with providers because of a complex mix of socioeconomic and cultural factors. The strategies outlined in this paper speak to the general importance of a nonjudgmental engagement style, accurate information, and consistent and reliable communication between care providers, patients, and caregivers in achieving effective patient engagement. Further research may focus on the needs and successful approaches for particular populations and/or health conditions.

Future studies may also explore whether providers who share the same race/ethnicity and socio-economic background as their patients help improve communication and interactions more systematically within organizations. Though we did not analyze communications by the type and credential of providers, it seems that front-line providers may help improve communication with other providers within a care team, rather than simply substituting or replacing communication

with other members of that team, while also lowering costs (Cross-Barnet et al., 2018). Further research is needed to explore this dynamic and as well as the extent to which initiatives aimed at improving communication among providers help improve patient/provider communication more generally.

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