

Thomas Jefferson University Jefferson Digital Commons

Department of Family & Community Medicine Faculty Papers

Department of Family & Community Medicine

8-2016

The Core of Care Management: The Role of Authentic Relationships in Caring for Patients with Frequent Hospitalizations.

Charlotte Grinberg
Thomas Jefferson University

Margaret Hawthorne
Camden Coalition of Healthcare Providers

Marianna LaNoue Thomas Jefferson University

Jeffrey Brenner Follow this and additional works at: https://idc.jefferson.edu/fmfp Camden Coalition of Healthcare Providers, Cooper Medical School of Rowan University

Part of the Family Medicine Commons

Dawn B Mautner vi how access to this document benefits you

Recommended Citation

Grinberg, Charlotte; Hawthorne, Margaret; LaNoue, Marianna; Brenner, Jeffrey; and Mautner, Dawn B, "The Core of Care Management: The Role of Authentic Relationships in Caring for Patients with Frequent Hospitalizations." (2016). *Department of Family & Community Medicine Faculty Papers*. Paper 44.

https://jdc.jefferson.edu/fmfp/44

This Article is brought to you for free and open access by the Jefferson Digital Commons. The Jefferson Digital Commons is a service of Thomas Jefferson University's Center for Teaching and Learning (CTL). The Commons is a showcase for Jefferson books and journals, peer-reviewed scholarly publications, unique historical collections from the University archives, and teaching tools. The Jefferson Digital Commons allows researchers and interested readers anywhere in the world to learn about and keep up to date with Jefferson scholarship. This article has been accepted for inclusion in Department of Family & Community Medicine Faculty Papers by an authorized administrator of the Jefferson Digital Commons. For more information, please contact: JeffersonDigitalCommons@jefferson.edu.

The Heart of Care Management: The Role of Authentic Relationships in Caring for Patients with Frequent Hospitalizations

Charlotte Grinberg, BA,¹ Margaret Hawthorne, MPH,² Marianna LaNoue, PhD,³ Jeffrey Brenner, MD,^{2,4} and Dawn Mautner, MD, MS³

ABSTRACT

In the movement to improve the health status of patients with multiple chronic conditions and vulnerabilities, while also reducing the need for hospitalizations, care management programs have garnered wide attention and support. The qualitative data presented in this paper sheds new light on previous studies regarding key components of successful care management programs. By going beyond a task- and temporal-based framework, our analysis identifies and defines the importance of authentic healing relationships in driving individual and systemic change.

Drawing on the voices of former clients of the Camden Coalition of Healthcare Providers, we identify the core elements of this authentic healing relationship, which is linked to patient motivation and active health management. Although not readily or reliably found in the traditional health care system and beyond, these authentic healing relationships present significant implications for addressing the persistent health-related needs of patients with frequent hospitalizations.

INTRODUCTION

Faced with accelerating health care costs within the United States, policymakers, clinicians, and researchers have grappled over the last several decades with efforts to both reduce spending and increase quality of care.¹ As frequent hospital utilization is considered to be a major contributor to the costs of health care, increased attention has been focused on the relatively small proportion of the population described as "high-risk" and "high-cost" (often referred to as "super utilizers," "frequent flyers," and "heavy users").² Despite a vast body of literature on one of the largest questions in health care policy and delivery, there remains a great deal of uncertainty with regards to the care needs of individuals with frequent hospitalizations and successful mechanisms to address these needs.^{3, 4} This paper is one in a larger series that utilizes data from interviews with former clients of the Camden Coalition of Healthcare Providers (CCHP) care management intervention to gain a more comprehensive understanding of these frequent healthcare users and targeted care management programs. Using qualitative methods, we draw on patient voices to identify and define the characteristics and role of authentic relationships in care management, an emergent concept currently missing in the literature on care management for patients with frequent hospitalizations.

¹Sidney Kimmel Medical College, Thomas Jefferson University, Philadelphia, Pennsylvania

²Camden Coalition of Healthcare Providers, Camden, New Jersey

³Department of Family and Community Medicine, Thomas Jefferson University, Philadelphia, Pennsylvania

⁴Urban Health Institute, Cooper Medical School of Rowan University, Camden, New Jersey

At the population level, studies have shown that people with multiple chronic illnesses and social vulnerabilities report and are documented to have much more frequent hospital use when compared with the general population.^{5, 6} Since the structure of the United States health care system is primarily designed to treat acute medical illnesses, patients with multiple chronic conditions and vulnerabilities must regularly navigate a complicated and fragmented system of different providers and conflicting knowledge.⁷ Common results include inappropriate, ineffective, or absent follow-up care, unnecessary duplication of tests, and inconsistent medication prescriptions with harmful interactions.^{8, 9}

In the movement to improve the health status of patients with multiple chronic conditions and vulnerabilities, while also reducing the need for hospitalizations, care management programs have garnered wide attention and support. In theory, care management is broadly defined as "a set of activities designed to assist patients and their support systems in managing medical conditions and related psychosocial problems more effectively." In reality, there is vast variability between the settings, durations, payers, philosophies, and protocols of care management interventions. The approach with patients and specific activities provided by these programs span a wide range, from telephonic care management by a single provider, to in-person home-based care management provided by integrated multi-disciplinary teams.

In an effort to identify the most effective care management models for patients with complex healthcare needs, the Synthesis Project of the Robert Wood Johnson Foundation published a landmark report that summarized the current literature. According to the data, care management programs targeting the hospital-to-home transition (a model that the Camden Coalition of Healthcare Providers follows) have had the most success in quality improvement and cost reduction. The report went on to identify in-person encounters, home visits, specially trained care managers with low caseloads, multidisciplinary teams, use of coaching, and presence of informal caregivers as key elements of successful care management programs.

This paper, by going beyond a task-based framework, identifies an additional critical element of success that is missing from the current literature on care management: the nuanced emotional experiences between patients and providers that drive individual and systemic change. Studies in a variety of disciplines examine and highlight the importance of relationships in caregiving, however, this is the first study, to our knowledge, to identify and detail the attributes and role of what we term "authentic healing relationships" in care management for patients with frequent hospitalizations. While a handful of studies have demonstrated that "continuous healing relationships," or physician-patient continuity, have demonstrated that "continuous healing relationships," or physician-patient continuity, have demonstrated that improved quality of care and decreased likelihood of future hospitalizations, have demonstrated that limited to the element of continuity. Our analysis on "authentic healing relationships" not only encompasses continuity, but also the non-temporal components of familiarity and genuineness.

The first section of this paper describes the qualitative study methods. The second section illustrates the medicosocial complexity of the sample population in order to contextualize the results of the study. The third section identifies the characteristics and role of authentic healing relationships by drawing on interviewee descriptions of care management teams, primary care offices, and hospitals. The fourth section explores the advantages and limitations of family and friend networks in fostering authentic healing relationships. Finally, the paper concludes with a discussion of the findings and policy recommendations to bolster authentic healing relationships in the formal health care system and beyond in order to improve the quality of longitudinal care for patients with frequent hospitalizations. While this study focuses on one city-based care management intervention, the lessons learned provide global insight into the needs of patients

with multiple chronic conditions and vulnerabilities and the relationships care management teams should foster to address health-related needs.

SETTING

The Camden Coalition of Healthcare Providers (CCHP) care management initiative is designed to reduce readmission for patients with multiple chronic conditions and vulnerabilities. CCHP has developed a citywide Health Information Exchange (HIE) that is used to facilitate data sharing between the three main hospitals in Camden, NJ. Real-time data feeds in the HIE are used by outreach staff to identify patients who are currently inpatient and potentially eligible for the intervention. Patients with two or more hospital admissions in the last six months are considered eligible for the care management initiative if they met at least three of the following criteria: two or more chronic conditions, five or more outpatient medications, difficulty accessing services, lack of social support, mental health comorbidity, active drug use, or homelessness. Once eligibility is determined, patients are enrolled in the CCHP care intervention only if they meet the additional inclusion criteria: currently insured, primary care provider in Camden, between the ages of 18-81, still admitted to the hospital at time of triage, and able to consent.

The care management initiative then sends a multidisciplinary team into the community to coordinate care for enrolled individuals for a 60-90 day period following hospital discharge. This care coordination includes an array of interventions customized to the patient's needs, including critical touch points of routine home visits, medication reconciliation, primary care and specialty appointment accompaniment, facilitating transportation to medical appointments, and assistance in applying for entitlements and benefits.¹⁸

The described approach of the CCHP intervention is community-based, patient-centered, and anchored in a trauma-informed framework. The care management teams provide care in the homes of patients, and utilize techniques of harm reduction and motivational interviewing to customize the intervention and decision making process. CCHP care delivery is informed by the understanding that past experiences, particularly related to trauma, have lasting effects on patient well-being, including functioning, physical, social and emotional health.

METHODS

Design

This study builds on prior qualitative work with former clients of CCHP. The first research team interviewed 19 former clients of CCHP and illustrated the psychosocial complexity of patients with frequent hospitalizations, including early-life trauma, unstable or violent relationships, and familial estrangement. The study highlighted how these psychological factors influenced care of self, access to care, and how patients interact with their care providers.¹⁹

This paper is based on a subanalysis of more recent interviews with 30 former clients of CCHP. The research team created a semi-structured instrument based on the first batch of interviews¹⁸ and input from staff members at CCHP. The questions in the instrument included the areas of employment and living situation, behavioral health risk, usual sources of care, adult protective factors, adverse childhood experiences, ability to recover from stress, perceived self-efficacy, and experiences with the CCHP. For questions asking for an affirmative, negative, or numerical response, planned prompts and probes were incorporated to extend the narratives. A

small number of the prompts were revised after the administration of a few interviews in response to confusion from interviewees. The data presented in this paper represents a subset of themes from the interview dataset.

Study Cohort

Thirty face-to-face in-depth interviews were completed with former clients of the CCHP care intervention according to the semi-structured interview guide. Non-English speaking clients were excluded from the study. Using contact information from the CCHP database, former clients were recruited to participate in this study beginning in June 2013. Interviewees had all been enrolled based on the utilization and eligibility criteria described above. Numerous calls were placed to contact eligible individuals who had worked with a CCHP care team between October 2012 and September 2014. Of the original potential participants who were called (n=133), 30 were interviewed in their homes (Figure 1). The demographics [Table 1] and medicosocial characteristics [Table 2] of the study sample population are statistically consistent with the attempted contact group and overall English speaking CCHP client population (except with regards to CCHP outcome status).

After consent was given, the interviews were conducted and audio recorded in English by investigators trained in qualitative interviewing techniques and human subjects protection. The interviews lasted between 30 and 60 minutes. The Institutional Review Boards of the University of Thomas Jefferson University and the Cooper Health System of Cooper University Hospital approved the study protocol.

Analysis

Recordings were professionally transcribed, deidentified, checked for accuracy, and analyzed using a general inductive approach to identify emergent themes. The purpose for using an inductive approach is to organically derive themes from raw data, rather than using hypotheses to predict outcomes. As transcripts became available, two investigators (CG and MH) conducted detailed readings of the interview transcripts to identify emergent themes. The analysis team discussed and refined these themes together; preliminary analysis occurred in this fashion until saturation was reached. Data saturation occurred after reviewing and discussing 20 interviews. These themes were used to generate and define inductive codes. The transcripts were then imported into the qualitative analysis software NVivo 10, where the two investigators independently coded the transcripts, with meetings to resolve discrepancies and reach consensus on preliminary and final codes. In rereading and organizing the codes, the researchers identified the overarching theme of characteristics and role of relationships in care management.

RESULTS

1. Medicosocial Complexity of Individuals with Multiple Chronic Conditions and Vulnerabilities

This study population is medically complex and their health care needs significant; they have multiple chronic conditions, they take several medications to manage these conditions, they have had repeated hospital stays and emergency department visits, and in general their health is poor.

It is noteworthy that all interviewees reported more than 5 medications, over 90% reported 5 or more chronic conditions, and over 80% reported their health as poor/fair [Table 1]. One interviewee illustrated the magnitude of medical complexity yet still categorized her health as fair: it's fair because I have like a lot going on...I have congestive heart failure, I have diabetes, I have um, neuropathy, I have cellulitis. I have all of that. In addition to having multiple chronic conditions and medications, over two-thirds of the interviewees live with mild or severe pain that limits daily activities and mobility [Table 2]. A preponderance of participants described pain frequency as constant (from the time I wake up to the time I go to sleep) and pain intensity as sharp, excruciating, and unbearable. The same participants went on to describe how their pain limits essential activities of daily living. As illustrated by one interviewee: It has made my life, where I have no life. I don't visit people because the pain is too bad...I...even when I try to do the crossing guard that's extremely painful, but I don't have a choice because the rent is so high.

As exemplified above, the study population and overall CCHP client population are medically complex; they live with multiple chronic conditions, numerous medications, poor health, and pain. Patients with this level of complexity must regularly navigate a fragmented health care system not designed to meet their needs often resulting in inappropriate and ineffective care.

Characteristics and Role of the Authentic Healing Relationship

While describing their experiences with the CCHP care management intervention, the theme of a unique authentic healing relationship emerged, which were not found elsewhere in interviewee descriptions of the formal health system. Although participants mentioned a number of task-based services provided by CCHP care teams, it was the relationships formed with their care team members that the participants spent the majority of time and emphasis recalling and reflecting. This relationship was often linked with motivation to engage in and sustain active health management. From these reflections, familiarity, genuineness, and continuity emerged as crucial ingredients in what we have identified as an authentic healing relationship.

Interviewees characterized relationships with their CCHP care teams as one where the staff member was both familiar (present, reliable, attentive, motivating) and genuine (nurturing, honest, respectful, and interested in the individual). Participants often drew a connection between this relationship and active motivation. In describing what she liked most about working with CCHP, an interviewee said: *Havin' people* [CCHP] *around, it was nice, um...goin' to the doctors, I really didn't care too much but I went anyway. Just to have them* [CCHP] *come around and sit and talk...is what I enjoyed.* The fact that team members visited clients in their homes created familiarity and, as one graduated client stated succinctly, *motivation to do better.* Without frequent health-related interactions, patients find it harder to trust and follow care instructions. In the words of one interviewee: *People doesn't pay attention to doctors, because they don't see them every day.*

In addition to familiarity, patients described genuineness as a key ingredient of their relationship with their CCHP care teams. As stated by one interviewee: I loved working with her. I'll work with her any day of the week, she was normal to me; she talked to me as a person, not as a patient. This genuine approach with patients was highlighted as a catalyst for change. As described by one patient, knowing that the care team was interested in me...it's like wow, me? I felt good, I felt better, I felt somebody really cares about me...I'm livin', and I'm not here by

myself. And I think that what's made me, you know, actually do it... I started takin' my medication, I started, you know, getting out.

The familiar and genuine relationships provided by CCHP care team members were not found elsewhere in participant descriptions of the formal health system. In contrast to the CCHP care team-client relationship, when interviewees spoke about their relationships with primary care offices or hospitals, the following elements of an authentic healing relationship did not emerge: presence, reliable, motivating, and interested in the individual. The remaining elements - attentive, honest, caring, respectful - sometimes emerged, but not as frequently as in descriptions of CCHP. The voices of former clients highlight this contrast between the different health relationships patients experience in different settings [Box 1].

BOX 1: Relationship Descriptions of Care Providers in Formal Healthcare System

CCHP Primary Care Office Hospital He knows my health condition, that's Nobody was explaining anything. Just to have them come around and sit and talk...is what I enjoyed. about it, but personally, no. [The care at the hospital is] perfect, She kept calling me, it got a little beautiful, they treat me nice. He is a pretty nice guy. He makes you annoving sometimes. feel comfortable and he asks you They wanted to cut my leg off. Never They stuck to their word. questions. talk to my husband. They don't talk to They took the time to listen, they took I ask the questions and he gives me an me; they don't talk to my doc. the time to explain. answer...That's what I do. *I got mistreated by the whole facility* They showed me how to bring myself Being that I don't seem him that much I and hospital. back. They showed me that they care. don't have a relationship. I went in the hospital for one thing, They was always honest with me they come out another thing. We ain't bonded. never sugar coated anything. The nurse at the clinic...She knows me Very polite...told who they were, pretty well. explained what they do. They give you medicine when they want She talked to me as a person, not a to. When you need medicine they don't patient. give it to you.

One explanation for the dearth of authentic healing relationships in primary care offices and hospitals is the lack of continuity in care delivery, a crucial element of the healing relationship. In discussing barriers to access to care, each patient narrative illustrated varying levels of fragmentation and discontinuity. Some particular challenges that emerge as a result of this fragmentation is that patients lack an understanding of their care provider networks, services are only temporarily offered before being discontinued, and follow-up care is unfulfilled. Many participants were unaware of the specific players in their health care networks; they could not provide the names and roles of their outpatient and inpatient care providers. Some interviewees described how offices rotate practitioners or locations too often to establish a meaningful relationship, others noted how providers are seen too infrequently or temporarily to develop a memorable rapport, and finally interviewees highlighted the large number of providers they have to visit each month. The consequences of discontinuity are significant. Fragmentation often leads to a misunderstanding of the particular services provided by each health practitioner, as well as undelivered promises made by providers in the formal health care system. In describing how the CCHP care team stuck to their word, one participant highlighted that in contrast with other providers: A lot of people say they going to do this and going to do that and they sell you a dream that is not true...someone come to me and social work says, "I am going to get you a wheelchair, a bathtub chair," and you be like, where is it? And it never come.

The discontinuity appears to be due, in part, to the temporality of services as predetermined by coverage and reimbursement. After describing a number of *terrible* experiences with her office-based primary care provider, one interviewee explained how she recently switched to a *very caring* home-based practitioner. Short and long-term continuity of care, however, is far from guaranteed. The participant first noted how the new practitioner *doesn't stay long...he only stays like 15 minutes. He [is] only allowed that.* The participant then expressed uncertainty over how long she would be able to receive care from this practitioner: *I had to go through them [new insurance provider] to get approved that I can get the house doctor and I am very well prepared just to keep this doctor. I don't know how long they allow me...So it is not a thing that I can get for permanent. Both access to insurance and the specific services covered by insurance emerged as primary determining factors of formal ongoing care delivery - at home, in the office, or at the hospital.*

Participants voiced a desire for and placed a value on continuity of care. Many interviewees described reliable follow-up care as a favorite aspect of working with the CCHP care team: When they'd promise me they'd be there...they were and that meant a lot to me. Other interviewees expressed sadness in no longer being able to work with their CCHP care team. Numerous participants asked for a CCHP care team to come back, to have follow-up after a year, or a step-down aspect to the program. A couple of individuals even described how they thought about going to the hospital to be able to work again with CCHP, although in reality the program is only available to patients once. Therefore, in addition to familiarity and genuineness, continuity was reinforced as an essential element of the authentic healing relationship.

It is important to note, however, that the CCHP care team intervention is not immune to discontinuity of care. In point of fact, the CCHP care teams were not always successful in reducing discontinuity of care, and in a number of cases, contributed to the fragmentation of health networks. Participants illustrated that discontinuous care within the CHHP intervention prohibited access to a previously established and desired authentic health-related relationship. One interviewee described a negative care experience when a staff member without a previous relationship performed the same tasks as a familiar staff member: [A CCHP staff member] showing up at my doctor's office, not even informing me that you're gonna be there and everything else...you're invading my privacy. I don't like that...I didn't even know who [they] were." In recommending changes to the CCHP care program, an interviewee stated: Maybe longer participation with the client because once they left the problem wasn't solved. They started but they didn't have enough time to solve it. Finally, the ability to sustain the impact of CCHPs care management intervention on active health management may hinge on continuity. One interviewee who described losing continuity with his CCHP care team summarized this observation: I used to look for them to give me my energy I need to keep things going properly. When they fell off I kinda fell off. When they were there I was more energetic maybe or persistent on doing what I was doing.

The CCHP care teams established authentic healing relationships with their patients. This relationship is linked to participant motivation to both engage in and sustain active management of health conditions. The three core elements of this relationship were identified as familiarity, genuineness, and continuity. Interviewees reported however that these elements were not always guaranteed with their CCHP care team and were not regularly found in hospitals and primary care offices. When one or more of these core elements were missing, authentic healing relationships and their associated positive impacts were in jeopardy.

In the section above, we identified three main elements of the authentic healing relationship: familiarity, genuineness, and continuity. Although first contextualized within the formal health care system, elements of the authentic healing relationship can be found beyond traditional health care providers and care management teams. This section explores the advantages and limitations of friend and family networks in developing authentic healing relationships.

It emerged from the interviews that friend and family networks are both essential to health care delivery and naturally contain an element of the authentic healing relationship: familiarity. Although the interviewees have multiple chronic conditions and complex health needs, when asked, "who cares for you?" more than half answered *family*. The majority of interviewees described the unpaid help provided by family members as related to eating, bathing, dressing, getting around the house (activities of daily living) and shopping, household chores, and driving (instrumental activities of daily living) - services not generally offered by the formal health care system, with the exclusion of home health aides. Other assistance described included making appointments and providing transportation to appointments (up to three times a week for dialysis), which are services only sometimes provided by the formal health care system. In the words of one participant who described the breadth of care received from family members: *My son helps me around the house and sometimes he helps me financially. My daughter is always making sure that I am okay health-wise. If I've got to get a doctor or something and I can't get there, she helps me get there.*

Although the element of familiarity exists in friend and family networks the other elements of genuineness and continuity may not always be found. Access to friend and family networks and personalities of both patients and their personal networks were identified as potential barriers to achieving genuineness and continuity.

With respect to access, a number of participants either described having no available support network or networks with competing priorities [Box 2]. As illustrated by an interviewee, when asked who is helping him through the process of switching practitioners, an interviewee said: *Oh myself. Everybody left me*. The sister-caregiver of another interviewee described having to balance raising her teenage daughter alone after *losing my mother and a marriage in the same year*, while providing care for her brother. When reflecting on all the care coordination once provided by the CCHP care team, the sister noted: *I would pay myself for doing that*. Finally, a number of interviewees described not being able to take care of themselves, because of their responsibility to take care of other family members. This lack of access to friend and family networks can result in non-existent or sporadic care that depends on the availability of family members, friends, and patients who have other obligations.

Finally, with respect to personality, a number of interviewees described not relying on their informal care networks either because of a desire or necessity for independence [Box 2]. Some participants noted how their desire to be independent, or their perception of independence, allowed for self-reliance. A handful of interviewees, on the other hand, noted how they had to be self-sufficient because they do not want to *burden* or *bother* family members and friends (including former CCHP care team members).

Access	My momma is in the nursing home right now. And she don't even love me and I take care of herwho pays for her insurance policies? I do. You know. They [two sisters] don't come to visit me. They know that I am sick. I don't have nobody to talk to. You know even when I try to talk to my daughter or my son, she don't even come around like that. And my son, he says, 'Oh mom, I don't want to hear that.'
Personality	My kids try, but they have children of their own, and they have to pay their bills, and they have to take care of their children. So I don't, you know, try to bother them. I can't even walk a whole half a blockI usually go to the stores that have the wheel carts. Because I am independent. I'd rather do it myself than to have people do it for me. Even though it's hard. It's nobody's fault, you can't blame nobody, I'm grown, they're all my problems, nobody else's.

In summary, friends and family members play an important role in the delivery of daily health care needs of people with multiple chronic conditions and vulnerabilities. Family and friend networks by their nature are familiar, a key aspect of the authentic healing relationship. However, family and friend networks are not always perceived as available or genuine, thus leaving significant gaps in access to medical and social services.

DISCUSSION

The authentic healing relationships established between CCHP care teams and their patients present significant implications for addressing the persistent health-related needs of patients with frequent inpatient hospitalizations. Authentic healing relationships were linked to patient motivation with regards to engaging in and sustaining active personal health management. Our analysis illustrates that familiarity, genuineness, and continuity are essential ingredients for building desired authentic healing relationships between providers and their patients. Parry et al. have similarly written about the importance of patient rapport with healthcare providers, concluding "that competence alone may be insufficient to engage patients in the self-management aspects" of care management and primary care interventions.²¹

Participants consistently reported that familiarity, genuineness, and continuity were not always guaranteed by their care management team, and were not readily found in primary care offices and hospitals. Our analysis also showed that when one or more ingredients were missing, authentic healing relationships, and their associated positive health impacts, were in jeopardy: interviewees lost their motivation in active health management.

Three broad policy implications can be derived from the experiences of the study participants. First, there is a need to shift beyond the traditional biomedical paradigm to one that acknowledges and sustains the role of authentic healing relationships in health care delivery. In order to provide and scale this relationship throughout the health care system, there is a need to first further understand the components that facilitate the formation of authentic healing relationships. Tools and techniques to foster and monitor this relationship need to be thoughtfully developed so it can be taught and replicated without jeopardizing the essence of the relationship. Training on authentic healing relationships should be integrated into healthcare professional training curricula and accreditation requirements to facilitate broad scale use of this relationship in health care delivery.

Second, it is necessary to design and expand services and assistance for family and friend caregivers, as well as direct-care workers (nurse aides, home health aides, and personal care aides). To date, "informal caregivers" lack educational, emotional, and financial support, which more often than not translates into psychological and physical burnout.²² While policy makers have called for and implemented caregiver support programs for elderly persons and disabled children (The National Family Caregiver Support Act),²³ our analysis demonstrates that there are individuals who fall between these two extreme age groups who also require substantial care and assistance in their homes. Moreover, while states are working to expand long-term care services, a bias remains toward institutional settings, especially nursing homes.²⁴ Public, private, and community organizations must therefore better support home-based services for patients at risk of frequent hospitalizations, regardless of age.

Third, care management programs must expand beyond a central focus on individual behavior change and/or troubleshooting access to care barriers in the formal health care system. ¹¹ Family and friends need to be considered essential players in care management and learn how to be active and effective participants in care planning and delivery. Since the vast majority of care management programs are currently transient in nature and do not guarantee the key element of continuity, training family and friends in care management (as well as expanding care management services for people without social support systems) would allow for the continued benefits of authentic healing relationships.

Our study has several noteworthy limitations. First, we focused on previous clients of the Camden Coalition of Healthcare Providers, an organization with clearly and narrowly defined inclusion/exclusion criteria, potentially limiting the generalizability of these findings. Our study only interviewed English-speaking clients and no homeless individuals were interviewed. Second, our sample size is small, though we did reach theoretical saturation as evidenced by no new codes being introduced in the ten final interviews. Finally, our sample may be biased as only 25% of previous CCHP clients called were successfully enrolled and interviewed. The interviewed subset significantly underrepresents individuals who did not graduate from the intervention.

SUMMARY

As a result of the lack of clarity around the attributes of patients with frequent hospitalizations, the elements of care management interventions, and the characteristics of relationships between care providers and patients, healthcare organizations still know little about the potentially modifiable challenges patients with frequent hospitalizations face during and after transient care management. In this paper, we sought to better understand the complex needs and health-related experiences of individuals with multiple chronic illnesses and vulnerabilities after participating in one city-based care management intervention: the Camden Coalition of Healthcare Providers (CCHP) in Camden, New Jersey.

The data presented in this paper sheds new light on previous studies regarding the importance of a continuous healing relationship in decreasing hospitalizations and improving access to care. Three core elements of this authentic healing relationship were identified as familiarity, genuineness, and continuity. Authentic healing relationships, however, are not readily or reliably found in the traditional health care system and beyond. Future research should seek to better understand how authentic healing relationships can be taught, sustained, and expanded. Policymakers, administrators, providers, and care management programs should

create stronger initiatives rooted in providing authentic healing relationships. A potential avenue for reform includes expanding services and assistance for family, friend, and direct-care workers, as they play an important role in fostering authentic healing relationships to improve the care and outcomes for patients who experience frequent hospitalizations.

WORKS CITED

- 1. Emanuel EJ. Where are the health care cost savings? JAMA: the journal of the American Medical Association. 2012;307(1):39-40.
- 2. Bodenheimer T, Berry-Millett R. Follow the money--controlling expenditures by improving care for patients needing costly services. The New England journal of medicine. 2009;361(16):1521-3.
- 3. LaCalle E, Rabin E. Frequent users of emergency departments: the myths, the data, and the policy implications. Annals of emergency medicine. 2010;56(1):42-8.
- 4. Pines JM, Asplin BR, Kaji AH, Lowe RA, Magid DJ, Raven M, et al. Frequent users of emergency department services: gaps in knowledge and a proposed research agenda. Academic emergency medicine: official journal of the Society for Academic Emergency Medicine. 2011;18(6):e64-
- 5. Kushel MB, Perry S, Bangsberg D, Clark R, Moss AR. Emergency department use among the homeless and marginally housed: results from a community-based study. American journal of public health. 2002;92(5):778-84.
- 6. Vogeli C, Shields AE, Lee TA, Gibson TB, Marder WD, Weiss KB, et al. Multiple chronic conditions: prevalence, health consequences, and implications for quality, care management, and costs. Journal of general internal medicine. 2007;22 Suppl 3:391-5.
- 7. Forster AJ, Murff HJ, Peterson JF, Gandhi TK, Bates DW. The incidence and severity of adverse events affecting patients after discharge from the hospital. Annals of internal medicine. 2003;138(3):161-
- 8. Schoen C, Osborn R, How SK, Doty MM, Peugh J. In chronic condition: experiences of patients with complex health care needs, in eight countries, 2008. Health affairs. 2009;28(1):w1-16.
- 9. Coleman EA. Falling through the cracks: challenges and opportunities for improving transitional care for persons with continuous complex care needs. Journal of the American Geriatrics Society. 2003;51(4):549-55.
- 10. Coleman K, Austin BT, Brach C, Wagner EH. Evidence on the Chronic Care Model in the new millennium. Health affairs. 2009;28(1):75-85.
- 11. Berry-Millett R, Bodenheimer TS. Care management of patients with complex health care needs. The Synthesis project Research synthesis report. 2009(19):2.
- 12. Weiss ME. Case Management. Disease Management and Health Outcomes. 1999;6(5):253-60.
- 13. Scott JG, Cohen D, DiCicco-Bloom B, Miller WL, Stange KC, Crabtree BF. Understanding healing relationships in primary care. The Annals of Family Medicine. 2009;6(4):315-322.
- 14. Institute of Medicine Health Care Quality Initiative. Crossing the quality chasm: a new health system for the twenty-first century. Washington DC: National Academy Press; 2001.
- 15. Gill JM, Mainous AG III. The role of provider continuity in preventing hospitalizations. Arch Fam Med. 1998;7:352–357.
- 16. Mainous AG III, Gill JM. The importance of continuity of care in the likelihood of future hospitalization: Is site of care equivalent to a primary clinician? Am J Public Health 1998;88:1539–1541.
- 17. Gill JM, Mainous AG III, Nsereko M. The effect of continuity of care on emergency department use. Arch Fam Med. 2000;9:333–338.
- 18. Mapping Our Progress: 2012 Annual Report Camden Coalition of Healthcare Providers 2012.
- 19. Mautner DB, Pang H, Brenner JC, Shea JA, Gross KS, Frasso R. Generating hypotheses about care needs of high utilizers: lessons from patient interviews. Population health management. 2013;16 Suppl 1:S26-33.

- 20. Thomas DR. A general inductive approach for analyzing qualitative evaluation data. American journal of evaluation. 2006;27(2):237-46.
- 21. Parry C, Kramer HM, Coleman EA. A qualitative exploration of a patient-centered coaching intervention to improve care transitions in chronically ill older adults. Home health care services quarterly. 2006;25(3-4):51.
- Donelan K, Hill CA, Hoffman C, Scoles K, Feldman PH, Levine C, Gould D. Challenged to care: Informal caregivers in a changing health system. Health Affairs. 2002;21(4), 222-231.
- 23. Levine C, Halper D, Peist A, Gould DA. Bridging troubled waters: family caregivers, transitions, and long-term care. Health affairs. 2010;29(1):116-24.
- 24. Institute of Medicine. Retooling for an aging America: building the health care workforce. Report Brief. Washington (DC): National Academies Press; 2008.