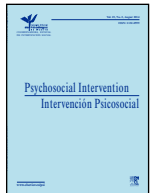




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Empowered and disempowered voices of low-income people with disabilities on the initiation of government-funded, managed health care

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ABSTRACT

The health and healthcare of vulnerable populations is an international concern. In 2011, a Midwestern state within the U.S. mandatorily transitioned 38,000 Medicaid recipients from a fee-for-service system into a managed care program in which managed care companies were contracted to provide recipients' healthcare for a capitated rate. In addition to cost savings through reductions in preventable and unnecessary hospital admissions, the goals of the managed care program (MCP) included: (1) access to a more functional support system, which can support high and medium risk users in the development of care plans and coordination of care, and (2) choice among competent providers. The population transitioned was a high-need, high-cost, low-income, and low-power group of individuals. The evaluation research team used focus groups as one of many strategies to understand the experience of users during the first two years of this complex change effort. The article explores empowerment in terms of users and their family caregivers' ability to make meaningful choices and access resources with regard to their healthcare. Specifically, factors empowering and disempowering users were identified within three thematic areas: (1) *enrollment experiences*, (2) *access to care* and (3) *communication with managed care organizations and providers*. While the change was not optional for users, a disempowering feature, there remained opportunities for other empowering and disempowering processes and outcomes through the transition and new managed care program. The results are from 74 participants: 65 users and 9 family caregivers in 11 focus groups and six interviews across two waves of data collection. MCP users felt disempowered by an initial lack of providers, difficulty with transportation to appointments, and challenges obtaining adequate medication. They felt empowered by having a choice of providers, good quality of transportation services and clear communication from providers and managed care organizations. Recommendations for increasing prospects for the empowerment of healthcare users with disabilities within a managed care environment are presented.

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La opinión autorizada y desautorizada de personas de bajos ingresos al iniciar la asistencia sanitaria gestionada financiada públicamente

RESUMEN

La salud y su atención en poblaciones vulnerables preocupa internacionalmente. Un Estado del medio-oeste estadounidense en 2011 traspasó obligatoriamente a 38.000 receptores de Medicaid de un sistema de pago por servicio a un programa de asistencia gestionada en el que se contrataba a empresas de asistencia gestionada para la prestación de asistencia sanitaria a los usuarios por una cuota por persona. Además de los ahorros por la disminución de admisiones hospitalarias evitables e innecesarias, los objetivos del programa gestionado de asistencia incluían: (1) el acceso a un sistema de apoyo más funcional para usuarios de un riesgo elevado y medio en el desarrollo de planes de asistencia y coordinación de la misma y (2) la elección entre proveedores competentes. La población a la que afecta este traspaso era un grupo de personas muy necesitadas, que entrañaban costes elevados, con un nivel bajo de ingresos y de poder. El equipo investigador de evaluación utilizó grupos de discusión como una de las muchas estrategias para entender la experiencia de los usuarios durante los dos primeros años de este esfuerzo complejo de cambio. El artículo explora el "empowerment" en cuanto a los usuarios y a la capacidad de quienes prestan asistencia a su fa-

Palabras clave
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Grupo marginado
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milia de tomar las decisiones oportunas y acceder a los recursos relativos la prestación de asistencia sanitaria. En concreto, los factores que reforzarían o debilitarían a los usuarios pueden pertenecer a tres áreas temáticas: (1) *experiencias de enrolamiento*, (2) *acceso a la asistencia* y (3) *la comunicación con las organizaciones con quienes proporcionan asistencia sanitaria gestionada*. A pesar de que el cambio no era optativo para los usuarios, un aspecto negativo, aún quedaba margen para otros procesos de capacitación, incapacitación y resultados gracias a la transición y al nuevo programa gestionado de asistencia. Se dispone de resultados de 74 participantes, 65 usuarios y 9 personas que prestan asistencia a la familia en 11 grupos de discusión, con 6 entrevistas en dos tandas de recogida de datos. Los usuarios del programa gestionado de asistencia sintieron desvalimiento por la falta inicial de proveedores, los problemas de transporte a las citas y para conseguir la medicación adecuada. En cambio se sintieron reforzados por el hecho de tener una gama de proveedores, una buena calidad de servicios de transporte y comunicación clara por parte de los proveedores y de las organizaciones de asistencia gestionada. Se ofrecen recomendaciones para mejorar las perspectivas de reforzamiento (empowerment) de los usuarios de asistencia sanitaria con discapacidades en un entorno de prestación gestionada de asistencia.

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Adequate health and healthcare for vulnerable populations is an international concern (Marmot, 2013). Since the 1980s, healthcare in the United States has changed dramatically (Centers for Medicare & Medicaid Services, n.d.) primarily due to increasing cost of healthcare services (Thorpe, Seiber, & Florence, 2001). More recently, since the Affordable Care Act was enacted in 2010, individuals are now mandated to have health insurance and are offered a federal health insurance option. Budget crunches and high costs have prompted a need for innovative ways to fund healthcare services in the U.S. (Jurkowski, Jovanovic, & Rowitz, 2002).

Simultaneously, government-funded health programs (i.e., Medicaid and Medicare) budgets are becoming an increasing financial burden. Medicare is the federal health program for people over 65 years of age who have paid into the country's social security system when they were working. Medicaid, while also established by the federal government, is administered differently in each state and eligibility is based upon income and disability status as opposed to age. Budget crunches and high costs have prompted a need for innovative ways to fund healthcare services in the U.S. (Jurkowski et al., 2002).

Along with rising healthcare costs, states struggle to balance budgets and compensate providers adequately, while also providing quality healthcare to vulnerable populations. A clearly superior model for funding healthcare at the state level has yet to emerge in the U.S. As Berenson and Rich (2010) note, the fee-for-service model has the tendency to overprovide, because there is little incentive to limit intervention. Overproviding creates a financial burden on the state and/or insurance companies, whereas capitation or paying per person as opposed to per service may incentivize withholding care. Berenson and Rich (2010) suggest creating a new alternative to balance between providing quality care while also avoiding a financial burden on the state and/or insurance companies.

One alternative healthcare funding model is the Integrated Health Networks in Latin America (Vázquez et al., 2009). This model promotes more streamlined and equal access to care. Conceptually, the model examines how the context and process may lead to outcomes of "equity of access, efficiency and continuity of care" (Vázquez et al., 2009, p. 362). One essential component of this model includes evaluating the quality of care coordination "through structure, process, and outcome indicators" (p. 364), as well as measuring continuity of care through the perspective of the user.

Other suggested healthcare models have started to focus on prevention, highlighting the need for consumers to be able to have control over their own care and improve self-management skills (Koh, Brach, Harris, & Parchman, 2013). The Health Literate Care Model, for example, would add patient health literacy to the already existing Chronic Care Model, which may encourage more communication between provider and patient as the provider works to ensure patients understand their health conditions and how to manage them.

With so many healthcare models available worldwide, finding a healthcare model that works for a given community's needs can be difficult, and indeed, many changes have been made in the past several years to the healthcare models available within the United States. One such model, managed care, has been spreading across the U.S.

Managed Care

Historically, managed care can be traced back to health management organizations (Dorsey, 1975). Over recent decades, individual states in the United States have adopted a managed care model to address budget limitations (Sekhri, 2000). As of 2010, 47 states had implemented some form of managed care that covered 71% of their Medicaid enrollees (National Association of States United for Aging and Disability, 2014). Although many of these states initially covered only healthcare services and excluded long term supports, recently, states have begun integrating both health and long-term services and supports into their managed care initiatives. As of 2011, there were 21 states using an integration of long-term services in their managed care programs – as of April 1, 2014, this increased to 28 states (Medicaid, 2014).

The-fee-for-service model has historically been geared more towards providing high cost specialist care than high quality primary care for patients, and there remains a shortage of primary care physicians in the U.S. today. Additionally, with the advancement of medicine and technology, there is an unprecedented amount of communication regarding preventive and wellness screenings and other information that primary care physicians may want to share with their patients.

Adult recipients eligible for Medicaid and not for Medicare (also called single-eligible recipients) are low-income and typically do not have a previous work history. Some individuals who are single-eligible may have had limited or no employment opportunities, making them particularly at-risk for chronic poverty, as well as continued use of Medicaid insurance (in contrast to opportunities to receive Medicare, private health insurance through an employer, or through the federally operated Marketplace). The adult Medicaid expansion is an opportunity for adults with and without disabilities to receive health coverage regardless of previous employment history. However, receiving Medicaid does not automatically guarantee that individuals will obtain or utilize necessary medical care. Low-income individuals may not seek care, or different types of providers (e.g., specialist physicians) may have long waiting periods or may not be taking new Medicaid patients. Therefore, for individuals who have chronic conditions or disabilities and need continual care, access to adequate, continuing, and comprehensive care may be particularly daunting. Individuals with chronic conditions and/or disabilities may have unusual medical needs, such as regular visits

with one or more specialists, and these needs may grow over time. Additionally, individuals who have higher or more complex medical needs may also have a greater need to maintain continuity of care with their providers (e.g., specialists). These issues may be heightened for many when a new system of healthcare is implemented, such as a transition from fee-for-service to managed care. This transition means that every user of the previous system needs to be a part of the communication process to find out whether their healthcare providers are going to be part of the new system, and if not, who will provide their care.

Empowerment

In principle, a managed care model provides support for users to take an active role in controlling their own care, through care coordination and choice in a connected network of providers. Managed care companies also provide users information via mail, online and phone communications. In this way, the efforts of managed care programs can be viewed as attempting to empower users. Empowerment is defined as a process by which people, organizations, and communities gain mastery over issues of concern to them in their lives (Rappaport, 1987). At the individual or psychological level, empowerment is a product of an individual's interaction with his or her context. Psychological empowerment includes beliefs that goals can be achieved, access to resources and awareness factors that hinder and/or enhance one's efforts to achieve those goals, and the information, communication and opportunity to make meaningful choices in the process (Zimmerman, 2000). In community psychology, empowerment is understood as a construct particularly and primarily salient for vulnerable groups who hold a marginalized position in society.

Considering that low-income individuals, individuals with disabilities, and the elderly have often been disenfranchised in healthcare contexts, an empowerment approach to both the implementation of the MCP and its evaluation are appropriate and useful. Recently, there have been calls for an increased emphasis on the “patient experience,” which covers a wide range of themes, including but not limited to accessibility, choice, specialist education and training, and service design (Hare, Law, & Brennan, 2006). Furthermore, Root and Stableford (1999) found that health insurance materials are at a higher reading level than the average literacy level of individuals who were transitioning from Medicaid to managed care, making it difficult to understand both the enrollment materials as well as the terms of the insurance plan and coverage. Good communication with providers is key to providing a positive healthcare experience, and poor interactions – rushed appointments, lack of communication skills, etc. – are linked with disempowerment, and conversely, respectful, effective communication – being honest, using patient-centered communication – has been linked to a feeling of empowerment among users (Croom et al., 2011; Kim, Kim, & Boren, 2008; Rohrer, Wilshusen, Adamson, & Merry, 2008).

Current Study

The current study includes users within a managed care program, which was recently implemented to address the challenges of budget restraints and quality of care. This particular pilot program of managed care has overarching goals of: 1) improving the quality of care through engaging users and reducing unnecessary hospitalizations, treatments, prescriptions, and/or services via a) care coordination, b) preventive services, and c) increasing visits to primary care physicians; and 2) reducing costs.

The current study defines empowerment as users taking control of their own health care needs and being able to communicate with and influence those providers and systems involved in meeting their healthcare needs. Disempowerment refers to users not having the opportunity to make their own healthcare decisions, the access to healthcare resources or the ability to advocate for and fulfill their own health care needs. At times, program users and caregivers express their empowerment and disempowerment in their statements of satisfaction and dissatisfaction about important program elements. The two focal research questions were: (1) what are the manifestations of MCP user empowerment regarding healthcare during the transition to managed care? and (2) what are the manifestations of MCP user disempowerment regarding their healthcare during the transition to managed care?

Method

Participants

Over the course of two years, 11 focus groups and 6 interviews were conducted, and included 65 users and 9 caregivers for a total of 74 participants. During the first year, the participants included 35 users and 5 caregivers in 6 focus groups and 2 interviews for a total of 40 participants. During the second year, the participants included 30 users and 4 caregivers in 5 focus groups and 4 interviews for a total of 34 participants. Initially all participants were recruited to participate in focus group interviews; however, some caregivers were unable to attend the group meetings and thus were interviewed individually. These users resided in six counties in a major metropolitan area in the state and indicated that their disabilities included physical disability, psychiatric disability, intellectual disability, blindness or visual impairments, deafness or hard of hearing, substance abuse, and/or chronic illness. Family caregivers were the parents of users with disabilities. See Table 1 for an overview of demographics for these 74 participants. In year 1, users had various disabilities which included: 59% physical, 29% mental health, 11% cognitive, and 3% unknown. In year 2, disability was reported by primary Medicaid qualifiers with some users selecting multiple primary qualifiers. Users indicated the following primary Medicaid qualifiers: 62% physical, 48% chronic, 17% mental health, 7% deaf, 3% blind, 3% substance abuse, and 3% other.

Table 1
Focus group demographics for year 1 and 2

User type	# of Focus groups/ interviews	Gender (N)	Age	Race/ ethnicity (N)	Total
Members Yr 1	5/1	Female: 49% (17) Male: 51% (18)	Range: 49–70 Median: 54	White: 23% (8) Black: 51% (18) Hispanic: 3% (1) N/A: 23% (8)	35
Caregivers Yr 1	1/1	Female: 100% (5)	Range: 53–71 Median: 55	Black: 100% (5)	5
Members Yr 2	5/0	Female: 63% (19) Male: 33% (10) N/A: 4% (1)	Range 30–88 Median: 56	White: 30% (9) Black: 70% (21)	30
Caregivers Yr 2	0/4	Female: 100% (4)	Range 37–62 Median: 60	White: 50% (2) Other: 25% (1) Unknown: 25% (1)	4
					74

MCP users and family caregivers were recruited by disseminating a flier through local disability advocacy and service organizations, group email lists of support groups, and direct phone calls using contact information provided by the state Department of Public Health. Finally, an MCP user survey offered users the option to indicate their interest in taking part in a focus group the following year.

Measures

The measures consisted of an extensive semi-structured focus group/interview guide, and a demographic questionnaire. The main topics covered in the guide included program transition, access to providers, quality of services, experience with care coordination staff, accessibility of providers, continuity of care, and accountability of managed care providers. The demographic form included gender, race, ethnicity, age, and primary and secondary Medicaid qualifiers.

Feedback from experts in the areas of focus groups, managed care, cultural competence, and disabilities informed development of the guide. In addition, an Evaluation Advisory Board made up of a diverse group of disability professionals and advocates appointed by the governor's office provided valuable input. The resulting guide was reviewed and approved by the leadership of the state Department of Public Health and the University Institutional Review Board.

Procedure

Experienced, trained facilitators used semi-structured guides to facilitate focus groups and interviews over the phone or at public, accessible locations throughout the six-county region being served (e.g., centers for independent living, university offices, public health offices, community agencies, etc.) from January 10, 2012 until November 7, 2013. At or prior to focus groups and interviews, research team members explained the study's purpose and obtained informed consent.

Facilitators recorded focus groups and interviews digitally and staff transcribed verbatim to create a transcript for analysis. Additionally, research team members took notes during the focus groups to capture contextual information that may or may not have been detected through transcription. Each focus group lasted between 70 and 180 minutes, and each interview lasted between 30 and 130 minutes. Following the focus groups and interviews, facilitators gave users \$50 as a token of appreciation for their time. The recordings were professionally transcribed, yielding 230 pages of focus group and 34 pages of interview data.

Analyses

The research team used qualitative analysis/coding software (Atlas.ti) to assist with a mixed approach (emergent codes and *a priori* codes) for qualitative analysis. Once all focus groups were completed and transcribed, a coding manual was developed. A combination of deductive and inductive coding (Auerbach & Silverstein, 2003) facilitated the identification of important constructs based on the focus group/interview guide, while also allowing themes to emerge organically. First, open coding was conducted on user transcripts by multiple researchers in order to identify overarching themes and subcategories. Themes and subcategories formed the basis of the codebook, which included definitions, examples, and inclusion/exclusion criteria. Next, researchers developed individual codes, requiring a minimum of two appearances for a code to be included in the final codebook. Then two coders applied the codebook to a portion of a user transcript. Through an iterative process, coders calculated kappa, discussed disagreements, adapted the codebook, and coded additional selections of transcripts, until codes covered all focus group material

and an acceptable kappa (.84) was achieved. After that, the researchers coded the remainder of user and caregiver transcripts.

Themes and quotes appearing here represent a small portion of illustrative comments. Only themes related to empowerment and disempowerment were included for the purposes of this study. For a set of comments to be considered a "theme," the concerns must have been raised by multiple stakeholders across groups. Each quote is indicative of other users' similar comments.

Results

Results of focus groups with users of the managed care program revealed empowering and disempowering themes for three distinct elements of the new system (see Figure 1). Initially, *enrollment experiences* in Year 1 regarding the period for selecting one of two managed care plans was of primary importance. Next, *access to care* through a variety of statements regarding the process of obtaining services was of major interest. Third, the quality and quantity of *communication with managed care organizations and providers* and the impact this communication had on users was discussed. The comments included are referring to aspects of the transition of the managed care program and/or the MCP itself that helped users feel more or less in control of their health care. It should be noted that users did not themselves use the term empowerment but rather referred to meaningful choice, as well as access to providers and provision of services and information, which are conceptualized in the empowerment literature and by the authors as elements of empowerment (Bond & Keys, 1993; Riger, 1993; Zimmerman, 2000).

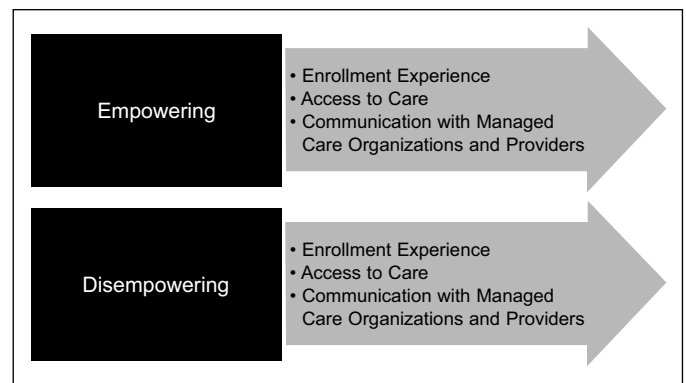


Figure 1. Empowering and disempowering themes

Enrollment Experiences

Empowering. During the enrollment process, some users and their family caregivers appreciated having what they perceived to be discernable choices between managed care companies that would be responsible for funding their care. Having a meaningful choice, i.e., a choice such that the user will be able to: a) discern the differences between the healthcare plans in terms of provider networks, access to services, and coverage of services, and b) choose a plan based on his/her healthcare needs and preferences is a sign of *empowerment*. The particular benefits that were illustrated were a key factor for some users in selecting a plan for healthcare. For example, one caregiver explained, "I chose MCO 1 over MCO 2 because it did give two dentals a year versus [the other company's] one." Additionally, some users selected an insurance company based on the listed hospital network. For example, "Two years ago when I had to make my choice, one of the things that I looked at [was] what hospitals are in the program" (Family caregiver). Therefore, knowing more about which plan offered certain services and options helped users to make an informed choice, leading them to feel empowered.

Disempowering. About 70% of users did not select one of the two managed care plans offered during the initial open enrollment period, so they were assigned to plan based on the state's algorithm for best fit with user needs and balance of enrollment between the plans. This enrollment process resulting in some users feeling *disempowered*. Reasons for not making this choice varied. Some users were not reached by the state due to inaccurate contact information. Low-income users often have transitory living arrangements. Others did receive contact from the Managed Care Organizations (MCOs), but were not responsive. At the outset, both MCOs were running new programs, and people had at best a modest basis for judgment to choose one or the other. One essential piece of information that was missing for many users was information about whether their current provider(s) would contract with one, both, or none of the MCOs under the new MCP. Before enrollment, many individuals did not have enough information to choose a plan that would definitely allow them to have continuity of care with their current providers. Considering one of the elements of an empowering enrollment process was the ability to choose a plan that included information of in-network providers, users found this situation to be disempowering. Overall, many users found it difficult to make an informed choice about which MCO to join.

Some users explained that the form in which they were contacted was not informative enough for them to make a choice. One user, for example, stated, "I do not read mail." The use of postal mail and lack of personal contact from the MCOs were problematic for many users who do not read their mail, which is mostly advertisements, and/or who may have relatively low literacy levels. Considering that mail was a key component of the MCO's communication about enrollment to users, this reliance on mail posed a hindrance to users selecting and fully understanding the two user care plans, as well as the other changes that came with the transition to managed care. Another user stated,

"I did not understand all the packet stuff [I received in the mail]... [the] packet of papers like this [showing thick stack of paper] and you could hold them side by side and see. But you didn't really know what it [being in one of the MCOs] was going to be like by the sheets of paper. And they said, 'Here is a list of doctors,' and I didn't know how, how are you supposed to pick a doctor by a list of names?"

This delivery of information led users to feel disempowered, since they were not able to make an informed decision on selecting a new provider and, in most cases, users did not want a new provider. Many users were not able to make a fully informed decision on which insurance plan to choose based on the ideal combination of in-network providers and the plan that would best serve personal needs and preferences. Managed care companies sought to enable users to maintain their relationships with previous providers who were not in network. They paid many out-of-network providers during this transition for their continuing services which, for users, was very helpful. However, users and caregivers were not always aware of this option, so they experienced disempowerment for some period of time.

Altogether, some users found that their experiences of enrollment were empowering in terms of knowing some of the benefits or services provided by each plan, as well as knowing that they could either keep their old provider or had easy access to new providers. However, many users found the enrollment experience disempowering because they were not able to discern between the plans in terms of provider networks and coverage of services. Moreover, they had difficulty obtaining enough information to be able to choose a plan based on their healthcare needs and preferences. If users were unable to find specialists who could treat their condition, these individuals, who are already low-income, struggled not only to find someone their MCO would reimburse who was equipped to treat their condition, but also to pay for any services that might be rendered that were not covered by their MCO.

Access to Care

Empowering. Access to care was considered empowering if it allowed users access to needed health-related supports, services, and/or providers. One component of the MCP that was empowering was the availability of transportation services to and from doctor's appointments, as well as visits to the pharmacy. The managed care companies heavily advertised and promoted their transportation services, so individuals were aware of and utilized the services. For example, one user stated, "But they always call you even if you have to [wait] and it's free, totally free. And I think that's a great idea. And [in addition to taking you to your medical appointments] they'll take you to the pharmacy to get your medicine too, for free, and home." In terms of the MCP goal of accessing functional support systems, about 1 in 6 users obtained transportation services on average more than monthly through their MCO. "[Transportation drivers] have given me their business card and I probably choose to ask for them. But I think they like me as much as I like them, so the ride is nice going such a long distance and coming back and forth." Some users felt *empowered* now that they had more control of and more resources for getting to and from appointments.

With regard to access to care as empowering via the available network of providers, some users mentioned that they were pleased with their access to new primary care providers (PCP). One user explained that once she was notified about her options and enrolled in the plan, "then I did a lot of calling back and forth to Medicaid and [her MCO] to find a new primary care doctor and that wasn't a problem."

Two of the goals to be achieved through having more users see PCPs were to reduce hospitalizations and unnecessary ER visits (i.e., before the MCP, users would go to an emergency room because they did not have a primary care provider). One user stated, "They [providers] take their time [and are careful and thorough]." Another explained, "My health is really improving [as a result of having access to a PCP]." A third user stated that they were happy with the access to new kinds of care and supports provided by managed care, stating, "I have had no problems for this year or the last year... I have got a physical disability and I just got approved for a personal assistant. Somebody to help me out at the house for like laundry and different stuff like that." These users were able to get greater access to care because they were able to see primary care providers and some also received personal assistants as a result of the MCP. Users felt empowered with improved access to care because they felt that they had greater support for improving their health.

Disempowering. Although some users reported the connection to transportation and primary care providers helpful in providing and/or improving access to care, some users felt disempowered, and that their access to care was worsened and/or limited by the MCP. These users felt *disempowered* because a lack of access due to challenges associated with transportation or because of not being able to find specialists in a reasonable amount of time or within a reasonable distance. Users reported feeling like they were subject to the will of transportation companies, some of whom would be late and/or make prolonged trips in order to pick up multiple passengers. For example,

"They (transportation services) try to pick up more people so it is less gas and I don't think they tell them (the managed care companies) that. She (transportation driver) said I am sitting out here (outside user's home). They are supposed to come in. It is dark. She come in, she gets me. She takes me all the way to parts of the city... There was altogether about 9 people in that van and a lot of them was sick, coughing their head off. I was in that van for like 3 hours" (User).

Users who had complex medical needs were not always able to find specialists who were in-network and had enough knowledge and training to treat them. For users who did have to find new

specialists because their previous ones did not participate in the new managed care plan, the process was often *disempowering* because they had difficulty in finding a new provider who could meet their needs as well as their previous one did. In one particular example, a caregiver had difficulty finding a provider who understood their daughter's atypical condition. One caregiver stated, "I still don't have an urologist who understands what her [daughter's] condition is. And I still don't know who I can go to for follow-up on the urology."

One significant issue in regards to access to care was the lack of initial network adequacy, including providers and hospitals. The two health insurance companies had difficulty in contracting with both providers and hospitals in year 1. This delay resulted in some users and family caregivers feeling *disempowered* and frustrated by their inability to access the care of their choice, including finding care that was nearby. One caregiver stated,

"There is no hospital close. Our previous hospital refused to be in the program. Our closest hospital and the second one we have gone to also is not [part of the network], so now the third one [that is in the network], I don't even know where it is, I have to figure [that] out in case of an emergency. Hope I can [get my son with a disability there] if he has a seizure."

Geography is not only important in terms of for convenience for users, but also in terms of actual feasibility of access to care. Having providers far away was particularly *disempowering* for users enrolled in the managed care plan (MCP) because of their low-income status, which may prohibit them from owning a vehicle, as well as limiting their ability to pay for transportation. Moreover, their medical conditions may limit their mobility. Many individuals relied on suburban public transportation, which is much less extensive than the city's public transit system, or they had to seek help from a family, a friend or the transportation provided by the managed care companies. Some individuals had cars and would drive to see their providers, with two users even purchasing a car in order to see their specialists. One user for whom transportation had repeatedly not arrived on time stated that "I did have a... problem with... getting someone to pick you up. So I bought a car so I could get around myself. So that was the answer to my problem," and another user stated that "I am now driving 50 miles... to go to a suburb, [for] every appointment in order to go to [Care Facility] for my mental health." These examples, while extreme, illustrate the importance to low-income users of having the option to continue with providers of their choice.

Some reported being "fed up" due to poor access to care, with two disempowered caregivers feeling almost hopeless about the MCP. They stated that they were ready to move,

"Families who have adult children with developmental disabilities are opting out and getting their own insurance or looking for other states to move to. Maybe my husband and I should join them" or potentially buy private health insurance, "I am so unhappy that what I really, really wanted to do is to get my daughter on her own private health insurance. I am to the point where I don't care how much it costs. I'll do it because I am so tired of this program, and we have worked so hard to get her where she is at to the age that she's at, [for] the state to mess that up because of some bureaucracy. Forget it."

Another added,

"Dr. 'X' is supposed to be her doctor, but basically she only got to see a physician's assistant. She did not see the actual doctor. The actual doctor has not come in and seen her. The physician's assistant runs it all. [Before the start of the MCP] at her old doctor, her doctor was in there" (Caregiver).

Therefore, some users still felt disempowered because they did not receive the same access to care as they had under the previous fee-for-service form of Medicaid. These comments speak to some users' and caregivers' disempowerment regarding access to care, and

primarily focus on the disruption in continuity of care in terms of being able to see the same provider(s) that they did before the MCP started.

Communication with MCOs and Providers

Empowering. Care coordination was an element of the managed care program that was designed to primarily promote two goals: 1) access to a more functional support system, which can support high and medium risk users in the development of care plans and coordination of care, 2) choice of providers. Additionally, care coordination is intended to empower users in the sense that someone is providing them support, information, and resources to help promote and maintain their health. More specifically, care coordinators were also there to help users find providers that were in-network, increase knowledge about managing chronic illnesses and, minimize unnecessary services. They also encourage users to see the necessary specialists and/or providers, as well as serve as support, and occasionally advocate, on the behalf of the user.

Some users reported that they did feel *empowered* by care coordination staff, particularly when compared to the previous Medicaid system. Since care coordination was a service that was new to many users, they reported more healthcare contact and greater access to needed resources (e.g., suggesting counseling or a different medication). Users reported feeling some control over their health when they had someone they could contact regardless of the need. "The reason why I say it's [managed care] easier is because every time you call they always have someone there that can direct your call for any situation. They always have someone there." Another user explained, "She [MCO care coordinator] knows my disability, psychologically, mentally, a little bit. And she's like my counselor. I trust her really good, and she calls me once a month. She speaks to them here [at the Center for Independent Living], too."

Another user spoke about her hospitalization and how the care coordinator helped empower her after her visit to improve availability of resources and prevent future hospitalization, stating,

"I was hospitalized. ...What my counselor and them wanted to do, is...to try to help me so I don't have to go back to the hospital; and that's what I like about it. That's the difference with the other Medicaid, they wasn't concerned about that, but they [the care coordinators with the MCO] want to see and find ways, like maybe counseling or medicine... so that you won't have to go back to the hospital."

In this sense, care coordination *empowered* users to practice self-care, as well as connect them to resources so that they could take control over their own health. Another user shared, "He [the physician] gets on me like if I go in and I tell him I forgot to bring my medication for the afternoon he says, 'Do you want to live?' I like the way he talks because I have congestive heart failure. I got to stay on top of [that]. He reminds me that I need to do this if I want to keep living. He can only do so much. He needs me to participate."

Additionally, some users felt they had improved communication under the MCP with their provider, resulting in an improved relationship, and empowered in the sense that they felt their health needs were supported and attended to by the provider. One user reported satisfaction with his provider (rheumatologist), reporting, "he understands. He is good. He takes time to listen. He doesn't just start writing the minute he comes through the door. He examines my knees. He had asked me about certain things about my health and how I have been."

Overall, providing support and information through care coordination and providers to users helped fulfill the MCP goal of creating a more functional support system. In particular, consistent communication with care coordinators and providers over time were *empowering* for users, helping them feel that they had sources knowledgeable about their condition of health.

Disempowering. Although many users found care coordination to be empowering in terms of increasing communication and strengthening the relationships between themselves, the MCOs, and their providers, when managed care staff were not responsive, some users felt unsettled and *disempowered*. One user stated “A couple of weeks ago when I had the cold and flu. I called [the MCO] to see where I had to go[for healthcare] and what was the procedure, and I ... was waiting and waiting and waiting [to get any response]. I was confused by the time...they still didn't get back to me...” Some users noted a disruption in the relationship with the care coordinator, stating, “she [care coordinator] was getting a sense of how I was managing my health and she was making suggestions. And I haven't heard from her since.” Users felt that the support that was once given to them was taken away, leading them to feel that they were now missing a valuable resource and therefore, felt disempowered. A number of care coordinators left their positions in the first year, creating continuity issues in providing ongoing care coordination that may have fostered such disempowerment.

When it came to prescription issues, some users felt *disempowered* by the lack of information and knowledge shared by the providers with the patients. These users emphasized the importance of learning about the history, needs and desires of users. They also emphasized that providers need to clearly state potential side effects and interactions of prescription medications with some users citing concerns that more prescriptions meant more side effects, ultimately adversely affecting their health. One user stated,

“They don't find out what your true history is and what you are taking along with it. [Previously] you have [had] to take medicine to take care of the side effects of another medicine that you are taking, and on top of that you have to get another medicine to bounce off of that. You take the three medicines. [Now with the MCP] you start with one (instead of the three you need) and something is wrong with that picture and it is done every day, but for them [the MCOs] it is cost effective and cheap.”

Although this particular issue may be indicative of the quality of the communication and relationship between provider and patient as well as or instead of an communication and policy issue with the MCP, it is important to note that users did not always feel empowered by their relationship with their provider and their MCO because some felt that their concerns were not being attended to. Users had mixed feelings as to whether they were receiving better care from providers as a result of the MCP. There were also communication issues between providers, about which users were understandably concerned, stating that, “My PCP doesn't necessarily communicate with my psychiatrist, I'm pretty sure they don't. That's something that has to be though? They need to communicate!”

Overall, when the communication among users, the MCOs and/or providers was unreceptive, unsupportive, and/or infrequent, users felt worse than when the communication was receptive, supportive, and frequent. Poor communication reduced users' access to resources and choice and thus felt disempowering for users.

Discussion

The current study explored empowerment and disempowerment from the users' perspectives of a top-down mandated change from Medicaid, a fee-for-service system, to managed care, capitated system. The goals of the MCP are 1) improving the quality of care through reducing unnecessary hospitalizations, treatments, prescriptions, and/or services via care coordination, and increasing visits to primary care physicians, and 2) reducing costs. Results of the current study indicate that, within the context of these goals, users struggled with the transition to managed care. Understanding that the change was top-down and that the MCP involved a fundamental systemic change in service delivery is integral to understanding the users' feelings of empowerment and disempowerment. Ultimately,

services under Medicaid, a fee-for-service system, were almost always approved, and now, under the MCP, approval is discretionary to the managed care organization. In general, users were more consistent, vehement, and illustrative when discussing the disempowering aspects in this mandated change to their health care than in discussing its empowering features.

Results of the current study suggest that the “patient experience” was of primary importance to users, similar to research by Hare et al. (2006), in which most users referred to aspects of their healthcare in terms of having or not having meaningful choices, access to resources and clear communication. These are core elements of empowerment for those experiencing important transitions such as a major change in the way healthcare is provided. This empowerment view of managed care has important implications for future changes in healthcare in terms of promoting choice, greater access to care, and quality communication that meets users' needs and preferences.

In the current study, most users did not choose a plan, and as a result were auto-assigned to one. This experience was many users' first exposure to the MCP, and may have set the tone for disempowerment. Although MCOs attempted to provide users with considerable information about their healthcare, many users were not able to make a meaningful choice within the MCP. In our project, similar to findings from a study by Drainoni et al. (2006), health insurance companies struggled with developing the provider network which led to concerns of delays in delivery of care, and issues with authorization of service. Although some users were able to continue to see their previous providers, some had to find new ones, which was problematic because some did not feel they had enough information to identify a quality local provider. Ultimately, these issues created some disruption in continuity of care, as well as disempowerment for users and caregivers. Without being able to stay with their previous providers, and without being able to learn more about the new in-network providers, it was very difficult for users to feel empowered in their choice. These results are consistent with Berenson and Rich's (2010) finding that capitation may incentivize withholding care, however indirectly. To mitigate user disempowerment, MCOs were quite flexible in paying out-of-network providers during the transition. Finally, although communication with MCOs in the form of a care coordinator is a potentially large benefit of the MCP, the role of the care coordinator presented issues for many users. Particularly within the initial transition, users were confused about the role of the care coordinator and struggled with the process of obtaining resources and information from their assigned care coordinators. In order to feel empowered in the future, users would need to be able to choose providers. Providing meaningful choices among attractive alternatives means managed care companies need to continue to build their networks, especially since continuity of care is linked to better outcomes for users, including those with more complex health needs. As Allen, Cappelletto, and Siegel (2012) illustrate in their review of three states' transition from traditional fee-for-service Medicaid to managed care, attempts to save money were predicted to adversely impact vulnerable populations, more specifically, the elderly and individuals with disabilities. It is essential to understand the challenges of a population who faces obstacles in terms of socioeconomic and health status. These include both lack of influence in general, and more specifically limited access to resources to organize against larger, top-down systemic (in this case, state policy) change. The challenges faced when managing disability or chronic illness can greatly impact one's ability for daily functioning, and being marginalized by socioeconomic status only further complicates matters in terms of health, quality of life, and access to resources. Because individuals with disabilities and/or chronic conditions have more complex and greater healthcare needs, they are at higher risk of being adversely affected by a major transition in their healthcare because it may disrupt continuity of care with providers, authorization

of services and prescriptions. Our results were consistent with these findings, such that users cited strongly disempowering experiences in their healthcare within the MCP.

It should be noted that some of the users included in the pilot are not only marginalized by income status and disability, but may also face additional marginalization because they identify as a racial and/or ethnic minority. In our study, 70% of users identified as Black/African American. As stated previously, this group is not only at risk of staying silenced, but also of facing a host of health disparities and a potential decreased quality of care (Betancourt, Green, Carrillo, & Ananeh-Firempong 2nd, 2003; Fiscella, Franks, Gold, & Clancy, 2000). In order to consider the broader meaning of this study, implications of the current study for theory, research, and practice will be explored.

Implications for Theory

The current study applied an empowerment perspective to healthcare needs of individuals transitioned to the MCP. Although users were not asked specifically about empowerment during the focus groups, their struggles and successes using the program reflected traditional definitions of empowerment: the role of choice and access to resources/information in feelings of control (Rappaport, 1981; Zimmerman, 2000). However, current results also suggest that empowerment is particularly difficult to achieve within a limiting system and a top-down transition, and aspects of empowerment may reflect those limitations. For example, we surmise that since users did not have a choice regarding whether or not the transition was going to occur, real choices in other capacities their managed healthcare were perceived to be especially meaningful.

The findings support the complexity theme in empowerment theory (Foster-Fishman, Salem, Chibnall, Legler, & Yapchai, 1998). For each area of service, users experienced a number of both empowering and disempowering events which could occur in proximity to one another. Clearly empowerment is a multifaceted construct that merits careful and thorough attention. A third implication for further theory is the relevance of empowerment in times of transitions. Transitions are likely to be times of change in power and empowerment as well. We need more thinking about how power and related empowerment change during transitions. In the transition studied here, for example, the role of informative, timely, understandable communication delivered in a culturally aware and accessible way provides a pathway to empowerment. More generally, we would anticipate the importance of communication to be heightened during a transition.

Implications for Research

Empowerment of users in healthcare settings is worthy of further empirical development. While Wallerstein and colleagues (cf. Wallerstein & Bernstein, 1994) have examined empowerment in public health, less has been done in community psychology to explore empowerment in healthcare for low-income individuals. This initial study is one of the few to date to explore the healthcare of low-income people with disabilities from an empowerment perspective. Moreover, the current study utilized traditional definitions of empowerment in its approach. Future research may examine definitions of empowerment and disempowerment within health care settings, including users' own definitions of empowerment in their healthcare. Users may also define empowerment differently from previous empowerment research, or identify aspects of empowerment unique to their healthcare context. In addition, future research would make a contribution by exploring issues of empowerment and disempowerment longitudinally to determine in what ways users become more and less empowered over time. Finally, multi-national studies of empowerment would help enhance

our understanding of how issues of user power in healthcare vary and are similar in different countries and cultures.

Implications for Practice

With regard to practice, one approach is to continue to promote care coordination in managed care. Considering that care coordinators were a relatively successful new component for users, and that communication was discussed as a critical element to feeling empowered, the role of care coordinators within the MCP should be promoted and expanded. Additionally, care coordinators should focus on encouraging users to advocate for themselves. Another avenue for promoting user empowerment so that they feel both a sense of control over their own well-being as well as being equipped to manage their condition, both providers and care coordinators should work synergistically to support users in obtaining the resources they need for their healthcare. Providers and care coordinators should also be adequately trained on how to serve low-income members of racial and ethnic minority groups with disabilities in a respectful, empowering manner.

For a group in Pennsylvania that transitioned from Medicaid to managed care, hospital admissions rates were reduced, as was the length of stay per visit (Bielaszka-DuVernay, 2011). Continuing and promoting care coordination does seem to reduce unnecessary hospitalization and, ultimately, may help drive down healthcare costs. Furthermore, if care coordinators can continue to be a primary point of contact for users and help them manage multiple health conditions, as well as encourage preventive measures, this support may help users to be more empowered with regard to their own personal health. Research with adults with mobility impairments indicates that health promotion interventions targeted at persons with a disability can increase quality of life and control healthcare costs (Ravesloot, Seekins, & White, 2005). However, a primary disempowering element of the transition was the fact that many users did not understand the new system and how it would affect them. It is quite possible that users may not have felt any more empowered by understanding that the healthcare system was changing for financial and political reasons. However, perhaps if the users had more advanced notice, as well as more accessible information about the transition and how it would change their healthcare, they would have felt they had more relevant knowledge regarding power arrangements.

Strengths

A primary strength of this study is the qualitative approach, which allowed individuals who have been marginalized in their healthcare experiences to have a voice in commenting on the transition to the MCP. Many focus group and interview participants commented on the value of the evaluation, and expressed their gratitude for the opportunity to share their perspectives and be heard. Additionally, focus groups and interviews included participants from various geographic areas and with a range of healthcare needs, which provided a nuanced look at the MCP's ability to serve diverse users. Finally, the fact that focus groups and interviews were conducted at different time points allowed for an understanding of the transition to the MCP over time.

Limitations

This study's limitations included issues around selection bias. Because the study participants were recruited by predominately English speakers who conducted the focus groups in English, there is an under-representation of non-native English speakers. Also, users with more serious disabilities were not able to travel to attend focus groups. Therefore, the empowerment and disempowerment themes

may not resonate to users who have more complicated disabilities. In addition, highly mobile families whose contact information was not current within the state's database, as well as users living in nursing facilities, were excluded from the study. Additionally, saturation was not possible with users of various ages and across disability. These focus groups were limited to suburban areas of a large city in the Midwestern United States and thus the transferability of findings may be limited to similar contexts. Finally, with conducting focus groups research it is a challenge to ensure all participants respond to focus group questions. To combat this, facilitators strived to engage participants who were less vocal during the focus group. However, there may be limitations on the breadth of empowerment and disempowerment themes, as more vocal participants tended to dominate the focus group session.

Conclusions

The voices of users of a new managed care pilot program were diverse and highlighted both the empowering and disempowering potential of managed care programs for users. Managed care through programs such as the one in the current study have the potential to improve coordination of services and support empowering processes for users who in the past may have struggled to navigate a fragmented health system. Furthermore, MCPs may promote user direction in care planning, making choices about treatment options or the hiring of support staff for users with disabilities. At the same time, MCPs tend to limit choices in terms of what doctors and hospitals users can access and the nature of managed care means that the managed care organization decides what care is deemed necessary and is ultimately provided. Therefore, it is challenging to be fully empowered with regard to one's own healthcare needs in this kind of system. Nonetheless, it is possible to be somewhat empowered with regard to one's own health care, with meaningful choice and access to adequate and high-quality care, through the communication and support of MCOs and healthcare providers.

Conflict of Interest

The authors of this article declare no conflict of interest.

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References

- Allen, E. P., Cappelletto, W., & Siegel, S. (2012). The impact of state Medicaid reform on vulnerable populations needing long-term care services and supports: An analysis of Florida, Illinois, and New Jersey. *NAELA Journal*, 8, 125–161.
- Auerbach, C. F., & Silverstein, L. B. (2003). *Qualitative data: An introduction to coding and analysis*. New York: New York University Press.
- Berenson, R. A., & Rich, E. C. (2010, May). US Approaches to physician payment: The deconstruction of primary care. *Journal of General Internal Medicine*, 25, 613–618. doi: 10.1007/s11606-010-1295-z
- Betancourt, J. R., Green, A. R., Carrillo, J. E., & Ananeh-Firempong 2nd, O. (2003). Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports*, 118, 293–302.
- Bielaszka-DuVernay, C. (2011). Improving the coordination of care for Medicaid beneficiaries in Pennsylvania. *Health Affairs*, 30, 426–430.
- Bond, M. A., & Keys, C. Empowerment, diversity, and collaboration: Promoting synergy on community boards. *American Journal of Community Psychology*, 21, 37–58.
- Centers for Medicare & Medicaid Services (n.d.). *Key milestones in CMS programs*.
- Croom, A., Wiebe, D. J., Berg, C. A., Lindsay, R., Donaldson, D., Foster, C., ... Swinyard, M. T. (2011). Adolescent and parent perceptions of patient-centered communication while managing type 1 diabetes. *Journal of pediatric psychology*, 36, 206–215.
- Dorsey, J. L. (1975). The Health Maintenance Organization Act of 1973 (PL 93-222) and prepaid group practice plans. *Medical Care*, 13, 1–9.
- Drainoni, M. -L., Lee-Hood, E., Tobias, C., Bachman, S. S., Andrew, J., & Maisels, L. (2006). Cross-disability experience of barriers to health-care access: Consumer perspectives. *Journal of Disability Policy Studies*, 17, 101–115.
- Fiscella, K., Franks, P., Gold, M. R., & Clancy, C. M. (2000). Inequality in quality: addressing socioeconomic, racial, and ethnic disparities in health care. *JAMA*, 283, 2579–2584.
- Foster-Fishman, P. G., Salem, D. A., Chibnall, S., Legler, R., & Yapchai, C. (1998). Empirical support for the critical assumptions of empowerment theory. *American Journal of Community Psychology*, 26, 507–536.
- Hare, C., Law, J., & Brennan, C. (2006). The vulnerable healthcare consumer: An interpretive synthesis of the patient experience literature. *International Journal of Consumer Studies* 37, 299–311. doi: 10.1111/jics.12006.
- Jurkowski, E., Jovanovic, B., & Rowitz, L. (2002). Leadership/citizen participation: perceived impact of advocacy activities by people with physical disabilities on access to health care, attendant care and social services. *Journal of Health & Social Policy*, 14, 49–61.
- Kim, S. C., Kim, S., & Boren, D. (2008). The quality of therapeutic alliance between patient and provider predicts general satisfaction. *Military Medicine*, 173, 85–90.
- Koh, H. K., Brach, C., Harris, L. M., & Parchman, M. L. (2013). A proposed 'health literate care model' would constitute a systems approach to improving patients' engagement in care. *Health Affairs* 32, 357–367. doi: 10.1377/hlthaff.2012.1205.
- Marmot, M. (2013). *Health inequalities in the European Union: Final report of a consortium*. Brussels: European Commission Directorate-General for Health and Consumers. ISBN 978-92-79-30898-7. doi: 10.2772/34426.
- Medicaid (2014). *HYPERLINK* <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Medicaid-Managed-Long-Term-Services-and-Supports-MLTSS.html>.
- National Association for States United for Aging and Disability (2014). <http://www.nasuaad.org>
- Rappaport, J. (1987). Terms of empowerment/exemplars of prevention: Toward a theory for community psychology. *American Journal of Community Psychology*, 15, 121–148.
- Raveslout, C., Seekins, T., & White, G. (2005). Living Well With a Disability health promotion intervention: improved health status for consumers and lower costs for health care policymakers. *Rehabilitation Psychology*, 50, 239–245.
- Riger, S. (1993). What's wrong with empowerment. *American Journal of Community Psychology*, 21, 279–291.
- Rohrer, J. E., Wilshusen, L., Adamson, S. C., & Merry, S. (2008). Patient centeredness, self-rated health, and patient empowerment: should providers spend more time communicating with their patients? *Journal of Evaluation in Clinical Practice*, 14, 548–551.
- Root, J., & Stableford, S. (1999). Easy-to-read consumer communications: a missing link in Medicaid managed care. *Journal of Health Politics, Policy and Law*, 24, 1–26.
- Sekhri, N. K. (2000). Managed Care: The US Experience. *Bulletin of the World Health Organization*, 78, 830–844.
- Thorpe, K. E., Seiber, E. E., & Florence, C. S. (2001, June). The impact of HMOs on hospital-based uncompensated care. *Journal of Health Politics, Policy, and Law*, 26, 543–555.
- Wallerstein, N. & Bernstein, E. (1994) Introduction to community empowerment, participatory education, and health. *Health Education Quarterly*, 21, 141–148. doi: 10.1177/109019819402100202
- Vázquez, M. L., Vargas, I., Unger, J., Mogollón, A., Silva, M., Rejane F., & Paepe, P. (2009). Integrated health care networks in Latin America: toward a conceptual framework for analysis. *Revista Panamericana de Salud Pública*, 26, 360–367.
- Zimmerman, M. A. (2000). Empowerment theory. In J. Rapaport & E. Seidman (Eds.), *Handbook of community psychology* (pp. 43–63). Springer US.