Research Article

Engaging in Coordination of Health and Disability Services as Described by Older Adults: Processes and Influential Factors

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Abstract

Purpose of the Study: There is little consensus on the definition and design of effective care coordination for older adults with chronic conditions, and the majority of care coordination models minimize the role and voice of older patients. Our objectives are to examine how older adults perceive and engage in the process of care coordination of health and disability support services and the factors that influence their engagement.

Design and Methods: Thirty-seven older adults with chronic conditions and 9 geriatric case managers participated in semistructured interviews that focused on older adults’ experiences with self-managing and coordinating their health and support services. Interview data were systematically analyzed for themes.

Results: The interview data revealed that involving older adults in care coordination is a complex, multistage process, conceptualized as making self-health assessments, making informed decisions about care, and executing and coordinating care. The findings indicate that a number of factors facilitate older adults’ decision and capacity to become involved in the coordination of their care, including their perceptions about how their condition impacted their everyday lives, and availability of intrinsic resources, tangible resources, and social network. Low perceptions of control over health and lack of such resources constrain their involvement.

Implications: Practitioners may facilitate older adults’ involvement in care coordination by using language with older patients that emphasizes psychosocial experiences in addition to medical symptomatology. They may also provide targeted support for patients with limited facilitating factors to promote involvement at multiple stages of the care coordination process.

Key Words: Care coordination, Chronic illness, Disability, Person-centered care, Health care systems and management, Home and community-based services
As the prevalence of chronic illness and disability increases with age, older adults typically increase their utilization of health and disability services, visiting a greater number of providers with growing frequency (Nie, Wang, Tracy, Moineddin, & Upshur, 2010). However, criticism persists regarding the quality of coordination in chronic care services (Boult, Green, et al., 2008; Golden, Tewary, Dang, & Roos, 2010). Improving care coordination has become a targeted goal from the Institute of Medicine (IOM, 2001). It has also been promoted by policymakers through the Patient Protection and Affordable Care Act (PPACA) of 2010 (Justice, 2010). Unfortunately, the literature provides little consensus on the effectiveness of care coordination (Bisantz et al., 2012), and little is known about how older adults perceive and actively contribute to the coordination of their care. Previous studies have identified a number of external factors related to care providers that can facilitate care coordination, whereas less is known about patient-related factors that contribute to care coordination. This study aimed at expanding our understanding of care coordination for older adults by examining how older adults perceive and engage in the process of care coordination of health and support services.

Background
Care Coordination for Older Adults
Need for Quality Care Coordination
An extensive network of medical and nonmedical support services has emerged to assist older adults in maintaining health and independent living. One in five Medicare beneficiaries visits a physician 13 times or more per year, and beneficiaries with two or more chronic conditions utilize 93% of all Medicare spending in 2012 (Centers for Medicare & Medicaid Services [CMS], 2012). In regards to disability support, more than 12 million Americans received home care services (National Association for Home Care & Hospice, 2010), and 10.8 million older adults received services under the Older Americans Act (Administration on Aging, 2010) in 2010. Given the number of providers who may be involved with any one older adult, effective coordination is needed to make appropriate clinical decisions, avoid duplicated services, provide effective services, and avoid medication errors.

Despite the potential benefits of the current network of health and disability services, there are concerns that the existing health care system does not emphasize preventative or coordinated care (Boult, Green, et al., 2008), and service recipients lack control over the long-term care services they receive (Ruggiano, 2012). These issues lead to rehospitalization (Jencks, 2009), declines in older adults’ function or health status, and increases in the cost of care (Golden, Roos, Silverman, & Beers, 2010; Jerant, Rahman, & Neshitt, 2001). Policymakers have recognized the value and need for care coordination. The PPACA of 2010 established a number of initiatives to facilitate care coordination for older adults with chronic conditions, including a Federal Coordinated Health Office that is tasked with advancing care coordination; the Medicare Special Needs Plan, which streamlines the funding and service delivery for those who are dual eligible for Medicare and Medicaid; and the person-centered Medical Home Model, which establishes multidisciplinary teams that support and coordinate services for those with chronic conditions (Justice, 2010).

Care Coordination Needs to Improve
Improving care coordination has been identified as one way of increasing the quality of health care and has been listed as one of the “priority areas for quality improvement” by the IOM (2001). The Agency for Healthcare Research and Quality (AHRQ) defines care coordination as:

“…the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.” (McDonald et al., 2010, p. 4)

The same source has identified a number of behaviors that contribute to care coordination, such as facilitating care transitions, assessing needs and goals, care planning, linking services and resources, and communicating across providers/services. All of these behaviors have been identified as care coordination tasks for which the responsibility lies among providers more than among consumers.

Despite the growing emphasis and increasing research on care coordination, the attributes of successful care coordination are unclear, with the literature providing little consensus on the conceptualization and effectiveness of care coordination models (Bisantz et al., 2012). This has been especially true regarding the role that patients play in care coordination. For instance, care coordination thus far has been primarily conceptualized as relating to the behaviors and activities of health care professionals, with the majority of research on care coordination for older adults examining the care coordination practices of health and supportive care providers (Chumbler, Mann, Wu, Schmid, & Kobb, 2004; Fairchild, Hogan, Smith, Portnow, & Bates, 2002; Peikes, Chen, Schore, & Brown, 2009).

Although there are currently a number of models and interventions addressing care coordination for older adults with chronic and complex conditions, in reality, these models provide patients with little control or say in the planning and management of health and disability services (Boult, Reider, et al., 2008; Counsell, Callahan, Buttar, Clark, & Frank, 2006). By not acknowledging the patient as a participant in care coordination, older adults are viewed as passive service recipients, and their activities and behaviors that contribute to the coordination of their health services.
and supportive care are minimized. Such a view of senior citizens consuming health care is contrary to the contemporary emergence of health care gold standards, such as participant direction, patient partnership, and person-centeredness of services.

**Older Adults as Active Participants in Health Care**

More recently, researchers and practitioners have recognized older adults as active participants in the delivery of health and disability services, rather than passive service users. For instance, chronic care self-management (Lorig et al., 2001) has emerged as a viable model that aims to educate patients, so that they can cope with symptoms, employ strategies for disease prevention, improve communication with providers, and gather and assess health information to make decisions about health (Stanford School of Medicine, 2013). Self-management programs have been associated with improved clinical outcomes for a number of chronic conditions (see reviews by Chodosh et al., 2005; Deakin, Welschen, Nijpels, & Singh, 2006) and have demonstrated to be effective among minority populations (Tomioka, Braun, Compton, & Tanoue, 2012). Also, studies on participant-directed services demonstrate that when older adults have greater control over the management of their care, they have fewer unreported needs and are more satisfied with their service (Carlson, Foster, Dale, & Brown, 2007; Foster, Brown, Phillips, Schore, & Carlson, 2003).

There is also growing emphasis for person-centeredness in health and disability support services, where patients’ interests, values, beliefs, and circumstances are integrated into service planning (Ruggiano & Edvardsson, 2013). Person-centered care for older adults requires providers to empower service recipients to coordinate and make informed decisions about their care (Lorig, 2012). For instance, Brock and colleagues’ (2013) study tested a care coordination intervention where older Medicare patients transitioning from the hospital to home were encouraged to play a large role in their care and found that this approach reduced hospital readmissions. Unfortunately, there are barriers to implementing effective person-centered care coordination because the current service systems have financial structures that do not reimburse for care coordination or patient education (IOM, 2008).

**Study Aims**

Prior work indicates that older adults receive chronic care within the context of a complex service system that requires coordination in order to provide effective care and avoid negative health and service outcomes. There is little consensus on the definition and design of effective care coordination, and the majority of models minimize the role and voice of older adults with chronic conditions. Findings indicate that older adults should play a central role in chronic care coordination, though there is a gap in the literature regarding their perspectives of the beliefs and perceived resources that influence the process of engaging and disengaging them in care coordination. Incorporating such information is essential for developing a more comprehensive conceptualization of chronic care, and improving care coordination overall. To expand existing knowledge, this study set out to examine how older adults perceive and engage in the process of care coordination of health and support services and the factors that influence their engagement. To address this aim, the following research questions were explored: “How do older adults with chronic conditions perceive care coordination? How do older adults and geriatric case managers perceive older adults’ role within the process of care coordination? What factors facilitate older adults’ involvement in care coordination?”

**Designs and Methods**

This study involved interviews with 37 older adults with chronic health conditions and disabilities and 9 geriatric case managers. In this paper, we present thematic findings that pertain to care coordination. The methods, forms, and interview guides for this study were approved by the institutional review board of [Florida International University].

**Study Sample**

**Older Adult Participants**

Thirty-seven community-dwelling older adults living in South and Central Florida participated in the study. Eligibility criteria were the following: being 60 years old or older, English-speaking, and having at least one chronic health condition or disability that requires ongoing support or medical care. Older adults who exhibited moderate to severe cognitive impairment were excluded from the study (as determined by the Mental Status Questionnaire [MSQ]) (Kahn, Goldfarb, Pollack, & Peck, 1960).

The sample of older adults varied: 25 (67.6%) were women; participants’ ages ranged from 60 to 97 (M = 76.5); 26 (70.3%) had a high school education or less; and 13 (35.1%) were Medicaid eligible or self-identified as Medicaid noneligible, with low income. In terms of race/ethnicity, 31 (83.8%) were white, 6 (16.2%) were African American or Afro-Caribbean, and 3 (8.1%) identified as Hispanic. Participants’ disability status varied as well, with chronic conditions including cardiovascular (hypertension, heart disease), diabetes, cancer, developmental disorders (cerebral palsy, Down’s syndrome), neurological (pain disorders, spinal injuries/paralysis), and blindness. Thirty-two participants (86.5%) had co-occurring conditions and 13 (35.1%) experienced the onset of their disability before turning the age of 60.

**Geriatric Case Managers**

After completing a number of interviews with older adults, the research team determined that it would be beneficial to also gather data from geriatric case managers. Nine
geriatric case managers participated in interviews. In terms of demographics, all but one were women, one was African American, and three identified as Hispanic. All of the case managers had completed graduate education, with eight holding Master of Social Work (MSW) degrees. The average number of years working in community-based settings with older adults was 10.41 and ranged from 4 to 28 years.

Recruitment

Participants were recruited through the Area Agency on Aging for Miami-Dade and Monroe Counties and community-based agencies that provide health and social services to older adults. Individuals who were interested in participating in an interview called the telephone number provided on a study flyer that was distributed by the agencies. Then, a member of the research team would explain the goals and details of the project and determine if the individual was eligible to participate in an interview. If the individual was eligible, the research team member would schedule an interview.

Data Collection

The lead author (N. Ruggiano) conducted in-depth interviews with eligible participants lasting between 45 and 90 min. Interviews took place within the participants’ home or an agreed-upon location within the community and were audio taped. Prior to each interview, participants were required to sign a consent form. The semistructured interviews included questions covering a variety of topics related to health and disability self-management, including their health-related behaviors, experience with health providers (i.e., doctors, nurses, specialists), support service providers (i.e., social workers, homemaker, and personal aides), and family and friends. “Care coordination” was not defined for older adults and was explored through a number of questions about how they assess their health, their role in decision making and developing care plans, how they identify and specify the roles of providers and informal supports, and how they navigate multiple providers and institutions as part of executing their care plan. Case managers were asked about their clients’ experiences with care coordination. Older adults were compensated with a $20 supermarket gift card, whereas geriatric case managers were compensated with $40 cash. The amount of honorarium to the older adults and case managers was reached in discussion with community partners as to an amount that was considered appropriate and equitable for these study populations.

Data Analysis

Interviews were transcribed and compared with the interview recordings for accuracy. Analysis involved a systematic process inspired by grounded theory (Glaser & Strauss, 1967) using ATLAS.ti (ver. 7) that began with open coding by the lead author, who unrestrictedly assigned key words and phrases to data segments that reflected the concepts those data segments represented (Strauss, 1987). Code generation was inductive and deductive, where a list of anticipated codes was created at the beginning of analysis and evolved over time as new codes emerged and codes that could not be linked to quotations from the interviews were deleted (Strauss, 1987). Data were assessed using constant comparison where individual codes were compared with previous data to assess for conceptual similarities and differences (Corbin & Strauss, 2008; Padgett, 2008). The second author (N. Shtompel) assessed the interview transcripts independently using the coding list created by the lead author, who added, altered, and deleted codes. This resulted in minor discrepancies in data analysis, which were resolved by discussing the codes until agreement was reached. Later in the analysis, thematic codes that were conceptually similar were linked together in broader, more abstract thematic statements (Corbin & Strauss, 2008). Within these larger themes, the researchers (N. Ruggiano, N. Shtompel, D. Edvardsson) examined the extent to which older adults’ and geriatric case managers’ perceptions were similar or dissimilar. Member checking was used to assess the validity of findings (Padgett, 2008). This involved the lead researcher revisiting four older adult participants, describing the major thematic findings from the data, and asking them to provide their perspectives on the accuracy of these themes. No discrepancies were reported by the participants.

Results

Overall, the results highlight that care coordination is a complex and challenging process, with multiple phases, requirements, decisions, and levels of engagement (see Figure 1). This process generally began with a self-assessment of health in order to reach the decision to seek support and initiate the process of seeking and coordinating care. This self-assessment was typically based on evaluations of self in relation to others and previous health experiences and was strongly influenced by factors such as the availability of resources and social networks for the older adult. The decision was then made to take or relinquish control over care, with older adults who perceived that they have considerable control over their health typically describing that they engaged in care coordination.

The process of engaging in care coordination then required participants to research, analyze, and synthesize information about their condition, symptoms, interventions, and services. The end result of this stage was the older adult making decisions about the plethora of services, interventions, and providers. The degree of involvement and success in this stage of the process seemed again to depend on factors such as the presence of resources and social networks for the individual. Fewer resources and networks meant less access to information and/or greater...
challenges to managing the complexity of information identified. The third stage of the process involved the actual coordination of services and highlighted its complexity and need of executive and managerial skills for the older adult to manage and coordinate care and services. The three stages and older adults’ use of resources within each stage are discussed in greater detail below.

Making Self-Health Assessments
Older adults described the first stage of care coordination as their self-assessment of health and disability. This assessment required a number of intrinsic resources, such as analytical skills and memory, and was described as an important part of care coordination, because the outcome of older adults’ assessment determined if they would seek out support for their condition. Older adults utilized two main benchmarks to assess their own health: normal aging and normal functioning. These were subjective assessments of health, and older adults reported that their own assessment sometimes differed from providers’ assessments of their health, which was often based on more objective medical assessments. This was confirmed by geriatric case managers, who stated that older adults often underreport their needs. In some cases, they also over-report their needs, as was reported by Ivy, a case manager, who stated, “We’ve had a few very highly-functioning clients think that they need homecare services every day. In actuality, when we assess their instrumental activities of daily living (IADLs) and activities of daily living (ADLs) we really see that they’re capable of still doing a great deal independently.”

Assessing Normal Aging
Most older adults indicated that declining health, declining function, and physical pain were normal aspects of aging. For instance, when Tammy (age 81) was asked if she had negative feelings about the declining function and mobility, she experienced after recovering from bone cancer, she replied, “No, I figure everybody has to have something.” In some cases, doctors facilitated this notion by explaining to older adults that new conditions they developed were “just a part of getting old.” This was demonstrated by Anna (age 94), who was asked if her providers explained the risk factors for Parkinson’s disease when she was recently diagnosed with the condition. She stated, “No, they don’t say. Age. They attribute everything to age. Everything is, ‘You’re old!’.” Participants indicated that when negative health changes were attributed to normal aging, they did not seek out support from providers.

The opposite of this trend emerged when older adults felt that their experience was outside of the boundaries of what was normal, because members of their social network have not had similar symptoms or conditions. In these cases, they could talk to their provider about their health “problem,” but the provider may consider their condition to be “normal” and not refer the older person for treatment, which was sometimes perceived as minimizing their condition. Such was the case with Dave (age 72), who disagreed with his prescribed treatment for a skin condition he felt was present for too long:

“I got dry skin. I’ve had that for 4 years. The other doctor, all he did was put hand cream on it, which ain’t doing nothin’. I talked to the nurse [at the senior center]. Her father has the same condition as I do...His clears up. The doctor have him some kind of medication so the skin clears up...Hand cream? [Shakes head.] It’s just hand lotion. That’s all it is.”

As indicated here, older adults regularly compared their own experience to those of members from their social
network in an effort to determine what is normal aging and what is not.

Assessing Normal Functioning
Older adults also assessed their health status in relation to “normal functioning” by comparing their present ability to complete IADLs to their prior ability. Participants expected a decline in function as they aged and did not consider a loss of function to be pathological if they could still complete the tasks with adjustments or increasing support. Support was sought when it was too painful to complete tasks or if they were no longer able to complete them with adjustments. For example, Elizabeth (age 62) explained that it was not until after her husband’s death that she realized that she was relying on pushing his wheelchair for balance support and finally talked to her doctor about getting a walker to help her walk. Sometimes these adjustments were quite extensive, such as for Lois (age 73), who insisted in providing self-care despite the fact that the process took her a long time due to her disability:

“Eventually I know that I’m going to have to depend on some type of service to help me, because a lot of things I can’t do…I can fully dress myself. It’s just frustrating to try to do it in a certain period of time. Where it might have taken me 30 minutes to get dressed when I was fully able to, now it probably takes me an hour and 30 minutes...Before I could just take my shirt and slip it over. But now I have to put my left hand in first and then stretch it over.”

When older adults used “normal functioning” as a benchmark, they could be experiencing a significant health problem but did not feel that it was severe enough to require treatment. Their ability to complete their regular activities was perceived as a reflection of their quality of life, and providers were viewed as overreacting when they suggested that the older adult receives support. Alfred (age 94) discussed how he disagreed with his doctor’s suggestion to receive homecare after he developed blindness from macular degeneration, “[My doctor] wanted to get me a nanny to take care of me...I guess at that time that’s what he thought, because I was 90. Anyway, I says, ‘Look, I don’t need anybody to scratch my back’.”

Disengaging or Engaging in Care Coordination
Once older adults determined that they were in need of services for their condition, their decision to be involved in care coordination depended on their perceived control over their condition. Those who did not feel that they had control over health relinquished control of coordination to providers, whereas those who felt that they had control over health reported that they were getting involved in care coordination. For participants who reported having co-occurring conditions, perceived level of control over health sometimes varied across conditions.

Relinquishing Control of One’s Health
Some older adults felt that they have little or no control over their health. In these cases, their involvement in care coordination ended with giving providers control over their care. The most common reason that older adults gave for relinquishing control over their care was their belief that providers were “the experts who will look after me.” One example of this was observed with Tom (age 84), who had blindness from macular degeneration:

“Sometimes when you’re sick and the doctor says, ‘Hey, listen! You got to do this or else...’ That’s it. You do what the doctor says. Because he’s the one that’s trained to do that, you know. You don’t want to argue and find out he was right and you were wrong.”

Geriatric case managers all observed this among their own clients, particularly when long-term clients asked the case manager to make decisions for them. Greg explained that one of the ongoing tasks as a case manager is to empower older adults to maintain decision making and control over their services. He stated, “After a few years, they’ll know me. They’ll [say], ‘I want you to review this [paperwork].’ [I reply,] ‘Well, what about you? What about your children?’ [They’ll say], ‘Well, I trust you’.”

Taking Control of One’s Health
In contrast, most participants felt that they had some level of control over their health. For instance, many acknowledged that they had control over their diet or exercise regimen, which affected their health. However, some older adults reported that their ability and experience with managing their chronic conditions gave them expertise in their personal health that providers did not possess. Here, older adults stated, “I know my body best,” such as Ferdinand (age 72), who explained why he was qualified to make decisions about his health, “Well, for one thing it’s me and my body, and the other thing is- I read [books].” Similarly, Valerie reported, “I can read my body. I know when I need to rest. I know when my blood pressure is high by a certain feeling that I have.”

Participants also reported, “I know what is best for me.” Such was the case of John (age 71), who complained that his post-surgery rehabilitation center would not give him control over the insulin regimen for his diabetes:

“[Sighs] They don’t give you anything but two, four, six or eight units. That’s not enough for me...I’m now taking sixty units in the day and they weren’t giving me more than maybe ten, twelve units at the most. And my blood sugar is rising. I usually keep it below about 150 or 160 and there it wouldn’t go below 150 or 160 it would woup up in the two and three hundreds.”

Making Informed Decisions about Care
This part of the process contained two dimensions, researching information and analyzing and synthesizing information.
Researching Information
For those who continued to engage in the care coordination process, the next stage involved making informed decisions about service options. This often began with gathering information about their health by consulting multiple providers, multiple media, and their social network. Geriatric case managers reported that they play a role in this process, either by helping their clients identify appropriate questions or sources to guide their research, or by directly answering their clients’ questions about their conditions and services.

Analyzing and Synthesizing Information
Once older adults collected information from these sources, the presence or absence of intrinsic resources (communication skills, information processing skills) was a factor that played a role in their ability to evaluate and integrate all of the varying information and strongly influenced a continued or discontinued engagement in care coordination. This process was challenging for older adults:

“[Michael, age 76] If you go to 10 physicians you got 10 different opinions [laughs]. Like you go to a mechanic with a problem, they have 10 different stories. And that’s why people have to educate themselves. A lot of people get really sick because they don’t check the medication. You have to be careful.”

“[Betsy, age 66] I agree with a lot of things [my oncologist] says, but I’m not really anemic. But he gave me this folic acid to give me iron. So I’m taking it. He told me to take it 3 times a day. The other doctor told me that’s too much. So I don’t take it 3 times a day. I take it once or twice.”

Older adults also reported that other influential factors for engaging or disengaging in care coordination included their social network and the extent to which it could provide support in synthesizing health information. Participants reported that peers (friends and siblings) were the most popular source to consult with about health service options. In the case of Maggie (age 89), she consulted her sister about basic health topics (cholesterol, blood pressure, etc.), most reported that they did not want to discuss their chronic illness or disability with family members. Many reported that they were reluctant to disclose information about their chronic conditions because they did not want their family members’ input or to become a burden to them. As Ivy, a case manager, explained, “Some of our clients are still looking to kind of protect their children. They don’t want them to know. They are very proud... They don’t really want their children to know that they are declining.”

Executing and Coordinating Care
Older adults engaged in a number of activities that involved coordination of multiple providers. The two most prominent themes that emerged from the data related to older adults executing their care include “facilitating interprovider communication” and “linking multiple services.”

Facilitating Interprovider Communication
Older adults and case managers reported that older adults were often tasked with transferring information across providers. Frequently, this happened when older adults must report the diagnoses, prescriptions, and assessments they had received from one provider to another. This often took place when older adults saw a new provider, followed through with a referral visit or test, or received information from the pharmacist. Some older adults acknowledged that their providers do not communicate well with one another:

“[Celia, age 74] I get a blood test from one doctor I take it to the other one. Because I know that they don’t talk to each other. At least I take one report to the other one, so that everybody has the same report. I find it’s better for me that way, because if anything comes up they can’t say they didn’t know because I’ve taken it to them personally.”

“[Valerie, age 74] I had gone to see the cardiologist and he ordered an echocardiogram… I brought it back so they could have a copy of it and whatnot. And I brought my lab work back so they could have a copy. And it says, ‘For infants and for patients over 70, this rate does not apply. It’s not applicable’. [The lab] did not indicate that to [me], neither with the doctor…I tried to tell [my primary care doctor], ‘It’s just a snapshot!’ Maybe I didn’t drink enough water or something. Who knows?”

As indicated from these examples, the process of facilitating interprovider communication required a number of factors such as intrinsic resources (organizational skills, memory, interpersonal communication skills) and tangible resources (computers, transportation, telephone or cell phone), and these factors were influential for the process of engaging in care coordination.

Linking Multiple Services or Providers
Older adults also reported that they often needed to orchestrate two or more services/providers to complete a single task for their chronic care needs. According to older adult and case manager participants, this was especially true for older adults who did not drive, because they had to negotiate their transportation with providers’ schedules.
for the purpose of meeting their health and supportive needs. One example was given by Shirley (age 77), who explained that the transportation service she used would always make her late to appointments or would pick her up before her appointment was complete. She later started to schedule the transportation much earlier or later than when she needed it so that she would not be stressed or rushed: “If my appointment is 11, I tell them 10:30 and I reach there by 11. When I’m due come home, say I’m in the doctor’s office for half-an-hour…I tell them like 2, 3 and I sit there…I prefer I do the waiting.”

A second way that older adults linked providers related to health insurance. Older adults in this study reported that consulting and negotiating with their health insurer for the purpose of accessing needed services was a common function of their health management. In many cases, their provider did not have up-to-date information about their coverage and the older adult had to confirm their coverage with the insurance company. Such was the case with Sophia (age 84), who wanted to get a shingles shot, but her physicians’ office told her (twice) that her insurance plan would not pay for it. She decided to call her insurance company to verify her coverage and learned that it was a covered expense. She said, “Not only did I get the check, I got the check for my girlfriend who was using the same doctor.” It was also common for older adults to consult with their insurance when there were changes in coverage that required them to change their physician. Once the last stage of care coordination was completed, older adults often returned to Stage 1 by reassessing their condition and continuing through the process of care coordination if they were not satisfied with the outcome.

Discussion

This study contributes to our understanding of chronic care for older adults by describing how they perceive and engage in the process of care coordination and which factors aid and obstruct the process of engagement. The interview data revealed that involving older adults in care coordination is a complex, multistage process conceptualized as making self-health assessments by assessing normal aging and functioning (Stage 1), disengaging or engaging in care coordination through relinquishing control of one’s health or taking control and making informed decisions about care (Stage 2), and by executing and coordinating care through facilitating interprovider communication and linking multiple services (Stage 3). Findings also suggest that availability of intrinsic resources, tangible resources, and social networks help facilitate older adults’ involvement in care coordination, whereas lack of such resources and low perceptions of control over health may act as barriers to their involvement. Several of the findings have implications for practitioners and need further exploration through research.

The Importance of Understanding Chronic Conditions and Experiences

One of the more important findings from this study was that older adults’ perceptions about how their chronic illnesses and disabilities impact their everyday life play a central role in their involvement in care coordination. For instance, participants in this study reported that they primarily assess their health or disability status by comparing the current impact of their condition on their everyday life with their prior experiences as well as the experiences of a “typical” person their age. This self-assessment is important, because older adults may not seek out treatment or become involved with care coordination unless they determine that there is a significant problem with their health. These findings support prior research showing that older adults tend to underreport pain symptoms, because they perceive their pain to be a part of normal aging (Maher et al., 2012). The study findings also indicate that older adults may underreport their declining mobility and function, because they also associate those experiences with normal aging and may not view loss of mobility and function as a problem if they are able to complete ADLs/IADLs with significant adjustments. Furthermore, because older adults vary in the daily activities that they use as benchmarks for their self-assessments, traditional assessments of physical function may be inadequate, because they are limited in the types of activities that are used as benchmarks for physical function (Marsh, Ip, Barnard, Wong, & Rejeski, 2011) and may not be relevant indicators based on the specific older person’s experience.

Findings from this study also indicate that older adults’ daily experiences with self-management of their chronic conditions may contribute to their level of confidence when navigating health and supportive care services. Participants acknowledged that they are not experts in medicine and social services but felt that their expertise lies within their understanding of having and managing their condition. When older adults perceived their experiences as not being valued, they were not confident in playing a large role in the planning and decision making of their services, unwilling to share their knowledge with providers and deferred the responsibility of care coordination to providers. In contrast, those who felt that their experiences were valued as important information in the care planning and decision-making processes reported that they would become involved in care coordination.

Overall, these findings contribute to a growing body of research that emphasizes the importance of incorporating older adults’ daily experiences in chronic care. Prior work has documented the value of incorporating older adults’ daily experiences in assessing successful aging (Romo et al., 2013); nursing home care (Taylor, Sims, & Haines, 2013); the coordination of hospital transitions (Manderson, McMurray, Piraino, & Stolee, 2012); collecting and maintaining personal health records (PHRs; Brennan, Downs, & Casper, 2010); and evaluating health and support services
(Giunta & Thomas, 2013). Prior findings on the effectiveness of care coordination have been mixed. Findings from this study highlight the possibility that older adults’ experiences and opportunities for self-management are an important, though missing, component of many existing care coordination models for older adults receiving health and home and community-based services for their chronic conditions.

The findings also align with prior research on the importance of provider-patient communication for older adults’ health and long-term care (Adelman, Greene, & Ory, 2000). When providers use language that emphasizes the medical aspects and symptomatology of older adults’ conditions rather than the psychosocial aspects of managing those conditions, they may create barriers to older adults’ participation in care coordination. First, this creates a barrier because older adults may not perceive their conditions as a set of medical jargon or symptoms, but a range of daily experiences and interactions. By not using language that emphasizes these experiences and interactions, providers may not be able to capture older adults’ full range of symptoms that may be considered when identifying chronic care and treatment options. Second, when providers minimize older adults’ psychosocial experiences, older adults may perceive that their own expertise is not valued and therefore feel discouraged from participating in care coordination. Finally, by minimizing older adults’ psychosocial experiences with chronic care self-management, providers are not able to assess older adults’ availability of resources needed to be full participants in care coordination. In this case, providers are not able to identify barriers to care coordination and provide older adults with support in overcoming these barriers. These findings align well with prior work on PHRs that has found that incorporating patients’ daily observations in their PHRs complements traditionally collected symptomatic information and gives a more complete view of patient health that can be used for clinical decision making (Brennan et al., 2010). It is suggested that providers may increase older adults’ involvement in their care coordination by: using language with older adults emphasizes one’s experience with managing a chronic condition and situates the condition in a life-world context, exploring the availability of factors facilitating engagement in care coordination, and providing targeted support where such factors are lacking.

Implications for Research

Although the study design includes a number of strategies for improving the trustworthiness of the data, the findings should be interpreted with caution, and further research is needed to better understand older adults’ involvement in the coordination of their care in other samples and settings. Specifically, there is a need to quantitatively examine the relationship between the factors that this study identified as influencing older adults’ participation in care coordination and their actual participation in the planning and decision making in care coordination. Further research should also establish the relationship between older adults’ involvement in care coordination and physical and mental health outcomes. Such research will provide further evidence to administrators, policymakers, and practitioners on the value of involving older adults in care coordination and directions for moving forward.

Conclusion

There are a number of approaches to care coordination in the literature. In order to improve service delivery for older adults with chronic care needs, we must move away from traditional models of care that view older adults as passive service recipients and providers as the single source of expertise and embrace person-centered models that encourage and support older adults to make informed decisions about their health and supportive services and value their perspectives and definitions of quality of life. Findings from the current study suggest that one of the initial ways of achieving such goals is improving patient–provider communication by using language that values older adults as experts in their chronic care and incorporates older adults’ daily experiences in clinical decision making.

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