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Transitions in Care among Older Adults Receiving Long Term Services and Supports

Mark P. Toles, PhD, RN,

John A. Hartford Foundation - Claire M. Fagin Fellow, Duke University School of Nursing, 307 Trent Drive, DUMC 3322, Durham, NC 27710, 919-684-1721

Katherine M. Abbott, PhD,

New Courtland Center for Transitions and Health, Penn Institute of Aging, University of Pennsylvania School of Nursing, 3615 Chestnut Street, #335, Philadelphia, PA 19104, abbott@nursing.upenn.edu, (215) 573-2013

Karen B. Hirschman, PhD, MSW, and

New Courtland Center for Transitions and Health, Penn Institute of Aging, University of Pennsylvania School of Nursing, 3615 Chestnut Street, #334, Philadelphia, PA 19104, hirschk@nursing.upenn.edu, (215) 573-3755

Mary D. Naylor, PhD, RN

Marian S. Ware Professor in Gerontology, Penn Institute of Aging, Director, New Courtland Center for Transitions and Health, University of Pennsylvania School of Nursing, 418 Curie Blvd, Claire M. Fagin Hall RM341, Philadelphia, PA 19104-4217, naylor@nursing.upenn.edu, (215) 898-6088

Background

Older adult recipients of long term services and supports (LTSS) are a medically vulnerable population with prolonged needs for supervision, services for health maintenance, and assistance with activities and independent activities of daily living (Reinhard, Kassner, Houser, & Mollica, 2011). For older LTSS recipients, acute changes in health and related transitions between hospitals and LTSS settings of care (e.g., nursing homes, assisted living facilities, care homes, care coordination programs, and their own homes) are common (Coleman, Min, Chomiak, & Kramer, 2004; Murtaugh & Litke, 2002). For example, nearly ten million older Medicare recipients are hospitalized each year, and among these, 20% are readmitted to hospitals within 30 days of hospital discharge (Jencks, Williams, & Coleman, 2009). Studies have shown that this revolving door between community and hospital settings is an independent risk factor for poor health outcomes among older adults and healthcare inefficiency (Coleman, 2003). In 2006, for example, the cost of hospital re-admissions for Medicare recipients over age 65 was estimated to be 17 billion dollars (Jencks, Williams, & Coleman, 2009).

A range of time-limited services, known as transitional care, fosters the safety and cost effectiveness of older adult transitions between settings and providers of care (Chiu & Newcomer, 2007; Coleman & Boulton, 2003; Kripalani, Jackson, Schnipper, & Coleman, 2007; M. D. Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011). Studies have shown that transitional care interventions (such as discharge planning, patient and family teaching, and home visits after discharge) improve continuity of care and prevent poor health outcomes among older adults (Coleman, Parry, Chalmers, & Min, 2006; Jack et al., 2009; M. D. Naylor et al., 2011; M. D. Naylor et al., 2004). To date, however, studies have not explored older adult and family caregiver perceptions of transitional care services received during transfers between LTSS and hospital settings. Studies have emphasized the importance of patient-centeredness in transitional care services (Coleman, Parry, Chalmers, & Min, 2006; Jack et al., 2009; M. D. Naylor et al., 2004), but few describe care recipient perceptions of transitional care services, thus, the preferences and needs of LTSS recipients remain uncertain. Moreover, lacking these care recipient voices, data are not available for accurately describing the barriers and facilitators to providing transitional care for older adults and their families. For example, it is not known what elements of transitional care LTSS recipients and family caregivers receive or wish to receive in LTSS settings before acute hospitalization and, during hospitalization, from their acute care nurses, physicians, and related staff.

Thus, the purpose of this study was to describe LTSS recipient and family caregiver perceptions of care provided during transitions between LTSS settings and hospitals for acute medical conditions (medical or surgical). We sought to understand: (a) their involvement in components of transitional care provided by professional staff in both LTSS settings and hospitals, and (b) their understanding of issues related to experiences with care provided by professional staff in both LTSS settings and hospitals. With findings and new understanding generated by this inquiry, we expected to provide guidance to steer nursing practice toward more patient-centered and family-centered approaches for providing transitional care for their LTSS patients. We also designed the study to learn more about the nature and types and transitional care interventions that could be applied to improve health outcomes for older adults and inefficiencies in healthcare services.

Method

Using a realist conceptual orientation to data collection and analysis (Miles & Huberman, 1994), we sought to understand stable patterns in transitional care by exploring participants' descriptions of their interactions with healthcare providers. Thus, we used a qualitative descriptive approach (Sandelowski, 2000, 2010) and conducted semi-structured interviews with a sample of informants. Study informants were purposively selected from a range of LTSS study sites (e.g., nursing homes (NH), assisted living facilities (ALF), and a Program of All Inclusive Care for the Elderly (PACE). All study procedures were reviewed and approved by the University Institutional Review Board.

Settings and Participants

Study data were collected in the Northeastern United States in publically funded, for profit, and not for profit hospitals and LTSS settings of care. In total, a sample of 57 participants were selected, including 30 nursing home (NH) residents (across seven NHs), 11 assisted living facility (ALF) residents (across five ALFs), 10 participants in a PACE Program, and six family caregivers of cognitively impaired residents in ALFs (n=3), and NHs (n=3). See Table 1. Demographic and length of stay information were collected from the medical records of LTSS recipients. In the sample, NH residents were on average 73.8 years old, predominantly female (23/30), and African American (22/30). ALF residents were older than NH residents; average age 84.6 years. ALF residents were predominately female (11/13) and Caucasian (13/13). The PACE members were a mean 75.2 years old, predominantly female (7/10), and African American (9/10).

Data Collection

Between July 2008 to April 2009, research assistants collaborated with LTSS site liaisons to identify older adults in NHs, ALFs, and receiving services through a PACE Program. Site liaisons notified research assistants of recently hospitalized patients and research assistants screened subjects for inclusion; the inclusion criteria were: (a) hospitalization within the past 30 days, (b) the ability to speak English; and (c) age at least 55 years, and (c) Mini Mental State Examination (MMSE) score of at least 18. A sample of 51 LTSS recipients was included in the study. During data collection, the opportunity emerged for interviews with family caregivers of LTSS recipients with moderate to severe cognitive impairment (MMSE<18). Thus, family caregivers were interviewed for information regarding their perceptions of the experience of moderately to severely impaired LTSS recipients who transitioned between hospitals and LTSS settings of care (n=6 family caregivers). Informed by available research, (Coleman & Williams, 2007; Greenwald & Jack, 2009; M. D. Naylor et al., 2009), an interview guide was developed and pilot tested before data collection began. After obtaining informed consent, research assistants used the interview guide and conducted face-to-face interviews (30 minutes to one hour in length) with study participants; research assistants had the ability to clarify questions with standardized probes. Research assistants made accommodations for interviews with LTSS recipients that were hard of hearing. Interviews were digitally recorded, professionally transcribed and reviewed with audio files and typed transcripts to assess the accuracy of transcription.

Data Analysis

Research team members read all interview transcripts and discussed patterns and potential themes in the data (Silverman & Marvasti, 2008). Using an open coding technique, the interviews were coded using Atlas.ti software (MPT) (Hsieh & Shannon, 2005). The process for coding interviews involved grouping of fragments of text related to individual themes and creating sub-themes through comparing and contrasting coded segments (Hsieh & Shannon, 2005). The accuracy and consistency of the initial coding were confirmed with redundant coding by a second team member (KBH). In a random sample of 10% of the interviews, the two coders agreed on 97% of coding decisions. Disagreements were resolved through consensus agreement. The codes included LTSS recipients or family caregiver's

descriptions of: (a) the rationale for transfer between LTSS settings and hospitals, (b) strategies employed by professional staff in LTSS settings and hospitals to engage LTSS recipients or family caregivers in care, and (c) LTSS recipient or family caregiver understanding of healthcare goals, decisions and plans. Coded data were further analyzed, using meaning condensation, which facilitated grouping fragments of interviews into larger thematic groups (Sandelowski & Barroso, 2003). When meaning condensation was completed for all fragments of data, we wrote thematic descriptions of LTSS recipient and family caregiver perceptions of involvement and response to involvement in transitional care were identified (Silverstein, Qin, Mercer, Fong, & Haydar, 2008). Research team members reviewed the thematic descriptions, made constant comparisons with the original interview transcripts, and used a team process to review the analysis and ensure that it reflected the data completely and accurately.

Results

LTSS recipients' perceptions of their transitions in care, to and from hospitals, were characterized by a common trajectory of contact with healthcare providers and movement across continuums of care. After acute changes in health, LTSS recipients (or family caregivers) described: (a) a brief interval of time for conversation with LTSS providers before hospital transfer, (b) the hospital transfer, usually by ambulance to a hospital emergency department, (c) the acute hospitalization, usually for several days, with opportunities for conversations with hospital staff representing multiple disciplines, and (d) the transfer back to LTSS settings of care. Across the full sample of interviews, we found that LTSS recipients and family caregivers had limited involvement in conversations regarding transitions in care (see Table 2). We also found that recipients were often uncertain about their care and wanted more information.

In our analysis, we identified three themes related to LTSS recipient and family caregiver involvement in components of transitional care: (1) before hospital transfer, limited involvement in planning with LTSS providers; (2) during hospitalization, limited engagement with professional hospital staff; and (3) uncertainty about hospital care and follow-up planning.

Before hospital transfer: Limited involvement in planning with LTSS providers

Professional staff frequently arranged transfers for LTSS recipients to hospitals without identifying or explaining the reasons for transfer to them (or their family caregivers). Notably, 37% of LTSS recipients and family caregivers (21/57) reported that no professional staff in LTSS settings spoke with them about acute changes in health or the reason for hospital transfer. As one nursing home resident told us, "They didn't really tell me what they were doing." When we asked LTSS recipients, "Who talked with you about going to the hospital," typical responses included the following: "Nobody. I guess I didn't have a choice;" "I didn't speak to anybody, the nurses sent me up...they automatically sent me up." Another said, "I didn't speak to anyone...just standard operating procedures for people...they just send them out to hospitals." Moreover, family caregivers also reported the desire for greater involvement in care, before hospital transfer. One family caregiver told us:

“I really see the PCP and the nursing home as the lynchpin for my mother’s care... I’m certainly capable of understanding more than ‘your mom is confused.’ I’d like someone to tell me what is really going on... they [staff in the nursing home] don’t feel they need to tell me what is going on. If she [my mother] has been incontinent - I want to know that. I want more of a 2-way conversation.”

In the absence of conversations with providers, LTSS recipients and family caregivers were uncertain about the reasons for transfers from LTSS to hospital settings of care. Some LTSS recipients clearly had no idea why they were hospitalized; for example, one nursing resident stated, “I really couldn’t tell you what happened to me or why I had to go to the hospital.” A second nursing home resident stated, “They didn’t really tell me what they were doing...my wife was concerned about my vital signs. I guess I went in for...for high blood pressure.” Very few LTSS recipients clearly understood why they were transferred to the hospital. One nursing home resident explained, “I’ve been bleeding from the uterus [for some time] and that makes the blood count low and...I don’t take blood that well. So I needed to go in.”

Family caregivers were also uncertain about LTSS recipient acute conditions and reasons for hospital transfer. This was a serious cause for family concern, particularly as 65% of LTSS recipients (20/57) were not accompanied during transfers from LTSS settings to emergency departments for evaluation. Family caregivers told us that they often did not speak with LTSS providers prior to these hospital transfers. They stated: “No. The nurses picked [my father] up from the floor...and sent him to the hospital. I don’t know why they sent him;” “No. They just called and told me that he went to the hospital;” and “No...they really couldn’t tell me anything...I think they weren’t ready to talk to me.”

During hospitalization: Limited involvement in planning with professional hospital staff

The median length of hospital stay was 4 days with a range of 1 to 42 days (data available for 51/57 LTSS recipients). Over these hospital stays, LTSS recipients and their family caregivers reported that involvement with hospital physicians, nurses and social workers was inconsistent and usually restricted. Nearly 30% of LTSS recipients (17/57) reported no conversations with a hospital physician regarding acute medical conditions or planned treatments. A nursing home resident stated, “...they didn’t have the time.” An assisted living resident stated, “I would have liked the doctor to tell me about my condition, he only came in to do tests...he never told me what my diagnosis was.” One nursing home resident echoed these remarks but added a telling adaptation she had made to limited involvement with her physicians. She stated, “They [physicians] don’t tell you that much, but you know you’re getting better if they keep taking things off.”

When LTSS residents did speak with their physicians (37/57), they consistently related appreciation about these opportunities to be involved in care. An assisted living resident told us, “The doctor seems very, very interested...He did call up my son to tell us what was going on - which I thought was very nice since we had no idea what was going on.” A family caregiver of an assisted living resident shared this sentiment, “He [the physician] talked to me about...her condition...they were trying to find where the infection was coming from - because he wasn’t sure...she had MRSA, a high temperature, her blood pressure was low and then her blood was low. It helped us.”

Only 33% (19/57) of LTSS recipients or family caregivers reported discussions about their medical condition with hospital nurses. One PACE program participant told us, “They just hooked me up to monitors and kept watching me...I don’t know if they read my chart or not.” Other LTSS recipients were far blunter: “the nurses ignore you;” “they don’t talk to you,” “they don’t tell you exactly what you need to know.” One nursing home patient added “It is nerve racking, nobody tells you nothing.”

Similarly, only 21% of LTSS recipients or family caregivers (12/57) reported discussions with hospital social workers. One recipient stated, “They kept saying, ‘social worker,’ ‘social worker,’ and I never saw her.” Another resident recounted her need to demand assistance, “At first they just told me that they were letting me go, but I said...that I ain’t leaving here until somebody talks to me.” To get information about hospital care and planning, recipients or family caregivers needed to initiate the conversation, which, in our sample, was a rare occurrence. Thus, to a striking degree, we found that LTSS recipients and family caregivers were bystanders in their hospital care.

Uncertainty about hospital care and follow-up planning

Due to inconsistencies or gaps in care, LTSS recipients and family caregivers in our sample needed to make sense of changes in health and treatments on their own. One family caregiver told us, “I have to ask the questions and be on top of things with my dad...They don’t just come to me with the information...” When asked, LTSS recipients and family caregivers expressed a strong desire for more information and explanations from their physicians, nurses and social workers. As described in Table 3, they also had clear ideas about the additional information and involvement in care they needed.

Foremost, LTSS recipients did not understand the nature and implications of their acute changes in health. An assisted living resident told us, “I think I had a bladder infection...I don’t know how to explain it...I think I ended up having a slight heart attack.” LTSS recipients questioned, “Why am I numb?” “Why was I so seriously throwing up?” and “What were they doing to me?” Moreover, LTSS recipients and family caregivers repeatedly described their desire to understand more about the nature of medical problems and related treatments. One assisted living facility resident wanted to know, “About me, my condition, you know what I mean. Do I need a follow-up?” Another needed to learn, “What I was taking? I never knew it.”

As hospital care completed, LTSS recipients and family caregivers wanted to know how to follow-up, who was going to help with follow-up, and what was going to happen next. Even broad changes in recipient’s discharge destination were not explained. A perplexed LTSS recipient asked, “Why, why was I brought back [to this nursing home]?” LTSS recipients also wanted someone to listen to their preferences in care. One NH resident shared, “The fact is...I wanted to go somewhere else...when they [crying] change my diaper here, they hurt my shoulder, they hurt me each time and my shoulders are sore.”

Discussion

Studies have repeatedly shown that failure to involve older adults and family caregivers in components of transitional care reduces their ability to manage healthcare needs after discharge, to adhere to recommended medical treatments and to participate in activities for improving physical function (Coleman & Berenson, 2004; Makaryus & Friedman, 2005; Robinson, 1999; Wetzels, Harmsen, Van Weel, Grol, & Wensing, 2007). In this study, we found that LTSS recipients and their family caregivers commonly reported limited opportunities to speak with their healthcare providers, let alone to participate in services designed to facilitate successful transitions in care. Almost half did not discuss care with their LTSS providers before hospital transfers. Nearly a third did not discuss hospital care with their physicians, and approximately two-thirds did not discuss hospital or aftercare plans with their hospital nurses or social workers. Further, in the absence of direct involvement in transitional care services, LTSS recipients and family caregivers understood neither acute changes in health nor the treatments and planned supports designed to address them. Thus, we found that LTSS recipients were often passive bystanders in their own care who wanted and needed more information and guidance.

These gaps in transitional care suggest opportunities for immediate improvements in care and very clear opportunities for nurses to engage, support, and empower older adults as they transition between LTSS and hospital settings of care. Foremost, our findings underscore the need for nurses to carefully talk with LTSS recipients and their family caregivers; more specifically, to talk with them about acute changes in health and the treatments being used to address them. Although large-scale change will be needed to address all the transitional care needs of older adults, nurses play a primary role in preparing older adults and family caregivers for transitions between providers or settings of care (Jack et al., 2009; M. D. Naylor et al., 2009; M.D. Naylor & Keating, 2008). In particular, nursing expertise and attention are required to deliver many fundamental elements of transitional care, such as (a) reconciling medications ordered in LTSS and hospital settings, (b) encouraging and activating LTSS recipients and family caregivers to take the next steps in care, (b) providing written plans, instructions and calendars to guide care after discharge, (c) teaching self-management skills, warning signs and appropriate responses to acute health changes, and (d) explaining discharge plans and follow-up (Hansen, Young, Hinami, Leung, & Williams, 2011; National Transitions of Care Coalition, 2008; M. D. Naylor et al., 2011).

The findings in this study also provide support for the use advance practice nurses or transitions coaches to deliver transitional care services for LTSS recipients and family caregivers. For example, with the support of transitional care nurses, plans of care can be coordinated between LTSS settings of care and hospitals to ensure continuity of care and communication of vital clinical information such as changes in medication. Though untested with LTSS recipients, transitional care nurses, such as those used in the Transitional Care Model (Naylor, 2004; Naylor et al., 1999), may be especially helpful for LTSS recipients with cognitive impairment or complex health needs (American Medical Directors Association, 2009; Naylor et al., 2007; Naylor, Kurtzman, & Pauly, 2009b). Thus, research is needed to test the effectiveness of evidence-based models of transitional care for supporting LTSS recipients as they transfer between providers and settings of care.

Study findings are limited by our exploratory research design and the collection of data from a small sample in limited geographic location. Study subjects were purposively selected from a range of LTSS settings of care (e.g., NH, ALF, and a PACE Program); thus, though our sample was not large, the diverse age, sex, race, and LTSS setting of subjects in our sample supported the aims of the exploratory research. Our findings were also limited by the design, which did not include observations or interviews with professional caregivers. An important next step in development of research to improve transitional care to support LTSS recipients will be to develop broader measures of care outcomes which incorporate the perceptions of recipients, caregivers, and professional staff members. Further, research will also be needed to explain how LTSS recipients' involvement in components of transitional care influences their understanding of their diagnoses and treatments. For example, intervention research, using the Transitional Care Model in LTSS settings of care, is needed to describe how transitional care interventions shape LTSS recipient health outcomes and post-discharge health services utilization.

In conclusion, we found that fundamental components of transitional care were not available to support older adult LTSS recipients and their family caregivers as they transferred transitions between providers and settings of care. LTSS recipients and family caregivers were often confused about the reasons for hospital transfers and their treatment plans during hospitalization and after their return to LTSS settings of care. These findings supported our recommendations for practicing nurse to discuss health changes and treatments with their LTSS patients often and for nursing researchers to explore new strategies for delivering transitional care for high risk LTSS recipients and their family caregivers.

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Table 1

LTSS Recipient Characteristics. N=57

Sex, n (%)	
Male	15 (26.8)
Female	41 (73.2)
Race	
African American/Black	36 (64.3)
White	20 (35.7)
Age, <i>years</i> , mean $\pm$ sd (range)*	76.2 $\pm$ 11.0 (58-100)
Type of LTSS, n (%)	
Nursing Home	33 (58.9)
Assisted Living Facility	13 (23.2)
PACE program	10 (17.9)
Length of Hospital Stay*	5.8 $\pm$ 7.3 (1-42)

LTSS = long term services and supports; NH = nursing home, ALF = Assisted Living Facility; PACE = Program for All Inclusive Care of the Elderly. Data unavailable for one LTSS recipient.

Table 2

LTSS Recipient Perceptions of Involvement in Transitional Care (n = 57)

	% Yes	% Unsure	% No
LTSS staff discussed reasons for hospital transfers	49	14	37
Hospital staff mentioned or discussed acute care with LTSS recipient or family caregiver:			
physicians	65	5	30
nurses	33	6	61
social workers	21	11	68

Table 3

Things LTSS recipients and family caregivers wanted to learn in the hospital

Diagnosis	<p>"I wanted to learn what I was doing there."</p> <p>"I was looking for the information on why am I numb."</p> <p>"They rushed in, gave me morphine, called the doctor ...they never gave me an explanation about it...if it was a heart attack."</p> <p>"...about the bladder infection. They didn't tell me what caused it."</p> <p>"Why I was throwing up. Why? Why was I so seriously throwing up?"</p> <p>"...my heart is only 30% beating...They didn't tell me exactly what's what. 30% beating? They should have told me more than that."</p>
Treatment	<p>"What they were doing to me?"</p> <p>"What I was taking? I never knew it."</p> <p>"About me, my condition, you know what I mean. Do I need a follow-up?"</p>
Referrals	<p>"I'd like to find out the situation, the why, why was I brought back [to this nursing home]."</p> <p>"Going home, or a better place, I know nothing...that makes no sense."</p> <p>"I want a physical therapist, if he just come 2 or 3 times a week it would help me to walk and that's all I'm interested in, to try to stand up."</p>