Transitions of Care

Perspectives of Patients Living in Long-Term Care

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Across studies, the risk of hospital transfer for nursing home residents is highest for people without documented advance directives and for people with chronic health conditions (eg, diabetes and congestive heart failure), mental health conditions (eg, depression), and limited functional abilities.[1] Care transitions can be disruptive, distressing, and potentially harmful for residents particularly when continuity of care is impacted by ineffective communication, medication errors, and lack of awareness of advance directives.[2-4] Although family engagement in care transitions is important, nursing home staff report feeling pressured by family members to transfer their resident to the hospital, which can result in unnecessary hospital transfers.[5] Similarly, although having a written advance directive is associated with fewer hospital transfers and subsequent admissions,[5] this alone does not guarantee the directive will be honored when needed.[6] Health care staff may be unaware of the presence of advance directives during medical emergencies.[5,7] Previous research highlights that care transitions can be improved by involving residents and their family in decision-making, discussing advance care plans before medical emergencies, and improving communication between providers, family members, and residents.[6,8-10]

While previous studies investigated care transitions between nursing facilities and hospitals,[2,11-14] only one examined transitions from the nursing home to the hospital and back,[15] and none examined the latter experience exclusively from the resident perspective. This study contributes to what is known about resident perspectives of care transitions from the nursing home to the hospital and back by exploring resident perspectives of communication prior to hospital transfer, whether choices for care were honored, family engagement during and after the transfer, and their overall experience with the hospital transfer.

METHODS

This exploratory research study used a nonexperimental design to examine resident perspectives of their most recent hospital transfer from a nursing home. A convenience sample of 14 participants living in nursing homes in the mid-western United States were recruited. This study is part of a larger project, the Missouri Quality Initiative (MOQI), to reduce avoidable hospitalizations through embedding advanced practice registered nurses (APRNs) into nursing facilities with innovative technology and a social work coach to improve care transitions.[16] Participants for this project were recruited from the 16 nursing MOQI facilities located in urban, suburban, and rural communities, which ranged in size from 120 to over 300 beds.

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This project is supported by grant number 1E1CMS331080 from the Centers for Medicare & Medicaid (CMS) Innovations Center and Medicare-Medicaid Coordination Office (http://innovation.cms.gov/initiatives/rahnfr/), which is focused on improving care and outcomes for Medicare-Medicaid enrollees residing in nursing facilities.

The content is solely the responsibility of the authors and does not necessarily represent the official views of the CMS. The authors acknowledge the gracious participation of 16 nursing homes in the St Louis area, their staff, the APRNs, and other staff of the MOQI Initiative.

The authors declare no conflicts of interest.

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's Web site (www.jncqjournal.com).

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Accepted for publication: January 30, 2020

Published ahead of print: March 5, 2020

DOI: 10.1097/NCQ.0000000000000478

Nursing staff, including the MOQI APRNs, were informed of the project and they provided study information to eligible participants. If a resident expressed interest in participating in the study, the MOQI social worker met with them to describe the study and obtain consent for participation. Eligible participants were required to be an enrolled MOQI participant, oriented to person, place, and time, have a recent hospital transfer (within the past 4 weeks), and answer questions about their transfer and perception of support surrounding care planning. If a participant was eligible and interested, the social worker interviewed the participant using a structured protocol. Interviews were audio-recorded and transcribed. The average length of the interview was approximately 30 minutes. Data were collected between November 2017 and March 2019.

In addition to interviews, resident-specific data collected for the MOQI project, described in detail elsewhere,[17] were used to provide context to the interview data. MOQI data included age, race, diagnoses at admission to the nursing facility, reason(s) for hospitalization, presence of an advance directive, resuscitation status, determination of hospitalization avoidability as determined the by MOQI APRN, and factors that impacted decisions to transfer were triangulated with structured interview data to provide context. For purposes of this analysis, these data were analyzed for any participant who completed an interview on hospital transfer.

Analysis

Multiple approaches to data analysis were used in this study. Descriptive statistics were used to describe the sample. A combination of content analysis and descriptive statistics were employed to explain participant perspectives and common occurrences within the sample. For this study, content analysis is summative and entails the systematic review of events outlined in participants' interviews. Summative content analysis involves exploring and identifying key events across participants and quantifying the events in order to contextualize and describe the sample.[18] Data were analyzed line by line to explore and categorize (code) responses; following initial coding, similar data were grouped, compared, and synthesized to create a comprehensive summary of participant experiences. The lead author conducted the data analysis independently. Data analysis and interpretation were discussed with the team member who conducted all of the interviews; discrepancies in interpretation were discussed until consensus was reached. Data analysis was managed using Nvivo 12 software (QSR International, Doncaster, Australia).

RESULTS

Participants ranged in age from 46 to 98 years, with an average age of 71 years. Ten participants identified as white and 4 identified as African American. The Supplemental Digital Content, Table, available at: http://links.lww.com/JNCQ/A707, outlines diagnoses at the time of admission to the nursing home. Primary diagnoses included end-stage renal disease (ESRD), cardiopulmonary disease, dementia, heart failure, schizophrenia, and multiple sclerosis. A full list is presented in the Supplemental Digital Content, Table, available at: http://links.lww.com/JNCQ/A707. Nine participants had a do-not-resuscitate order in their charts at the time of transfer while 5 were full code. Twelve of the transfers resulted in hospitalizations, 1 resulted in an observation stay, and 1 was an emergency department only visit. MOQI APRNs deemed half of the transfers to be avoidable.

Many residents were unsure why they were hospitalized due to confusion at the time of transfer; however, others recalled and described transfers related to broken bones from a fall, kidney infection, urinary tract infection, and gastrointestinal (GI) complications. Data collected by MOQI APRNs provided more detail about reasons for participant transfers such as ESRD, anemia, sepsis, pneumonia, GI bleeding, chest pains, and dehydration. Other factors impacting reasons for transfer included resident or family preference for transfer, nursing facilities not having the in-house resources to address the issues, primary care provider or staff insisting on transfer, and staff expertise or comfort managing the condition in the facility. All variables are outlined by participant study ID number in the Supplemental Digital Content, Table, available at: http://links.lww.com/JNCQ/A707.

Communication about hospitalization

Participants' perception of communication about the need for hospitalization prior to their transfer varied. Six participants recalled an emergency situation with no discussion about the decision to hospitalize. Other participants

(n = 5) recalled the nursing home staff discussing possible hospitalization with them or family members as part of a decision-making process prior to the transfer. Although some participants were not able to remember (n = 3), the majority remembered discussing whether hospitalization was needed. Responses ranged from being unwilling to be admitted as with one of the participants ("I'm not going unless I absolutely have to") to a willingness to consider the health care team's opinion: "You know more than what I know … So, what do you guys think? I trust your opinions." A few participants were encouraged by staff to go to the hospital as illustrated by this comment: "We think you ought to go. Just to get this crap cleared up."

Advance directives

Half of the participants reported they had a written advance directive; however, only a few were confident in their response. Participants answered: "I'm not sure but I think I do have an advance directive"; "I'm sure"; and "I think I do." Most participants did not or were unsure whether they participated in advance care planning meetings or discussions at the nursing facility at some point during their stay. However, several participants recalled planning meetings involving the nursing team and their family members. One participant did not perceive the need for advance directives: "I can speak for myself … I'm always going to be able to speak for myself … If I didn't want the NG nasogastric tube I would have told them … but what had to be done, had to be done."

Most participants perceived their family members fully supported their wishes and would honor their advance directives. Any discord that participants perceived arose from family members not agreeing with each other about the most appropriate care; for example, "My brother, sister and dad, they don't think that he can take care of me at home." Another participant reported family members were not open to discussing advance directives that involve anything other than the resident being full code: "My daughter or my son don't like the idea of not … bringing me back … they lost their dad. He had lung cancer … they want me … to do what they can to bring me back."

Study participants were also unsure whether hospital staff were aware of their advance directives; for example, "I'm not really sure about that." It was also unclear to participants whether they worked with a palliative care team while hospitalized. Participants recalled: "I was pretty sick so I don't remember too much," and "I guess I'm not really sure. There were so many people in and out." However, one participant told staff his wishes to remain alive through all possible intervention in order to care for his young daughter. He perceived the hospital heard his wishes and treated him accordingly.

Transition back to the nursing home

Participants were asked to discuss their experiences being discharged from the hospital. Most replied that they were ready to leave and perceived the discharge as fine or good. Three participants were provided with specific instructions following discharge including seeing their cardiologist and discussing medication changes with their nursing home staff. One participant perceived she was not ready for discharge so after talking with the hospital staff, her discharge was delayed several days. Another participant felt "pushed, thrown out" and reported that discharge instructions were not provided due to living in the nursing facility: "Knowing that I was coming back to the nursing home facility, I guess they felt they didn't have to tell me anything."

Similar to the experience of being discharged from the hospital, most participants perceived the transition back to the nursing home as being fine or good. For participants who did not experience a smooth transition, they noted treatment changes were made in the hospital and were not adequately coordinated with the nursing home staff, which disrupted the transition home. For example, one participant described that medications were adjusted during the hospital stay: "They took me off of Cymbalta, which you're not supposed to just stop taking it. You're supposed to wean off of it. They didn't. But I got that back yesterday." Another participant reported asking the nursing staff and physician at the nursing home to get back on her medication after she returned. On the nursing home-side, participants noted a change in rooms at the home when they returned and reported feeling isolated making the transition home challenging. For example, one participant reported: "Nursing facility staff don't care if you're eating. They don't care about anything. Just get her in the bed and let her alone. That's how they act." These statements indicated that the residents

experienced their own adjustments and disruptions moving from the hospital back to the nursing facility.

DISCUSSION

The majority of residents reported having a positive experience with their transition from skilled nursing facilities to the hospital and back. Most participants felt that they were included in key decisions and informed about their care and treatment, which supports findings from previous research, suggesting involvement of older adults and family members leads to a smoother transition process.[9,10,15] In this study, the manner in which the resident was treated at each facility transition and attention to the residents' needs throughout the transition process made a positive difference in their perception of the overall transition. For the most part, facilities involved in the transitions practiced patient-centered care, as indicated by the comments made by participants. However, there were inconsistencies reported about hospital discharge where nursing home residents were not always included in the discharge plan; rather, study participants perceived the hospital staff only communicated about the discharge plan directly with nursing home staff. Those participants who reported negative transition experiences also reported a lack of involvement in the transition process, and inconsistent communication with both transferring facilities, which can lead to a disruption in quality care.

One of the most significant findings was the number of residents who were not able to recall whether they had an advance directive. The inability to remember this detail may be related to the general confusion that residents reported in the transition process. However, for residents who were able to recall details of the transition process and could not recall the existence of an advance directive, ongoing discussion and review of existing advance directives might improve their memory and provide an opportunity to change wishes, if warranted. Regular discussion about advance directives could also increase older adults' understanding of the purpose of an advance directive. In previous research, family members found relaying the patient's advance directives or wishes was challenging due to communication barriers between the nursing facility and hospital staff and between the family and hospital staff.[11] Finding solutions to these barriers through technology or standard practice strategies (ie, asking if a patient has advance directive upon admission and using it to frame treatment discussions, so advanced directives can be changed if needed) is essential to breaking down these barriers.

Family members and residents play an active role in discussions surrounding hospital transfers. Previous research highlights that family members perceive the need for hospitalization when they believe nursing homes have limited capacity for medical care including not responding quickly enough to changing conditions[11]; in this work, advance directives were not considered by the family in hospital transfer decisions unless the family perceived the patient's condition to be life-threatening. In the current project, while most residents were confident that their family and loved ones would honor their wishes and the terms of the advance directives, others reported concern about whether their family would actually carry out the directives as indicated due to disagreements within the family about the patient's stated wishes. When such conflicts are identified in nursing facilities, it is important that these conflicts and disagreements between family members are addressed with a health professional, such as a social worker, prior to emergency situations. Resolving issues before a crisis will help to ensure a smoother transition process, and also increases the likelihood that the older adults' treatment choices will be honored. Participants in this study were admitted into the nursing facility with complex medical conditions. Having early and frequent discussions about the types of intervention residents want and including key family members in these discussions is important to reduce conflict during medical emergencies.

Implications

Based on findings from this study, it is recommended that staff, families, and residents be proactive in having advance care discussions early and frequently with residents at admission and throughout their stay, including during the transfer process. It is also recommended that the care team and families work together with the residents to identify their needs and wishes from a medical, social, and psychological perspective. Master's-prepared social workers are well qualified to conduct family meetings alongside other clinical staff and are equipped

to manage family conflict that can arise from the advanced care planning process.[19] Identifying goals of care that the resident, family, and staff agree on requires that all stakeholders have an understanding of the following: (1) the major health issues, prognosis, and treatment and care options; (2) resident wishes for their care; and (3) nursing facility capabilities to manage residents in the home.

Hospitals and nursing homes can both improve on communication strategies through insuring that completed advance directive documents travel with participants electronically or in paper form. When wishes are not documented, it is important for hospital staff to ask residents and family members about their wishes for care in the event a medical emergency arises. During medical emergencies, communication about resident wishes for their care can be tricky. This makes consistent and frequent communication about wishes and goals for care so important, particularly at care planning meetings with residents while they are in the homes, prior to medical emergencies.

Some participants in this project recalled discussing the possibility of transfer with the nursing staff. To improve communication with staff, residents, and family members, it is important to discuss options for care in the nursing home prior to transfers with residents and designated family members. Residents and family may not be aware of what nursing home staff can do in the home. Discussing care options, explaining the risks and benefits of transfer, and explaining the physician and nursing recommendations for transfer will ensure that the resident and family are actively involved in transfer decisions.

Limitations

Given that the nature of this study was a content analysis and descriptive statistics of interviews and administrative data with a sample size of 14 residents, the results of this study are not highly generalizable. Participants in this analysis were also a part of a larger intervention with embedded APRNs in nursing homes and specific strategies utilized to improve care transitions. Their experiences with hospital transfers may be different from people living in nursing homes that are not a part of the larger project. The age of the population group studied, the timing of the interviews (eg, after an acute medical crisis), and their medical and/or cognitive functioning may have hindered people from engaging in long and lively interviews as well as their recall of the transfer event. The results, however, provide important insights into resident perceptions of the care transition process involving skilled nursing facilities and hospitals. Additional research with a larger sample and across geographical areas and care settings is needed and may result in different findings.

CONCLUSION

Care transition from nursing facilities to hospitals is a particularly vulnerable time for residents. Participants in this study had several complex medical and mental health conditions, making communication and coordination at the time of transfer critical for their health and recovery. Absent from the literature is a clear understanding of resident experiences during transfer including communication from staff and use of advance directives in guiding care. Key findings from this study include a resident's general confusion surrounding advance directives but an overall positive experience with their transfer experience when nursing home and hospital staff provided residents with direct and clear communication. Further research is needed to examine these findings with a larger sample of nursing home residents.

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