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Patient Preferences for Information on Post-Acute Care Services

Justine S. Sefcik, MS, RN [Doctoral Candidate, Ruth L. Kirschstein Predoctoral Fellow],
F31NR015693, University of Pennsylvania School of Nursing, Philadelphia, PA,
jsefcik@nursing.upenn.edu

Rebecca H. Nock, BSN, RN [Ruth L. Kirschstein Predoctoral Fellow],
T32NR009356, Center for Integrative Science in Aging and, NewCourtland Center for Transitions and Health, University of Pennsylvania School of Nursing, Philadelphia, PA,
rnock@nursing.upenn.edu

Emilia J. Flores, BSN, BSE, RN [Predoctoral Fellow, Hillman Scholar in Nursing Innovation],
Center for Integrative Science in Aging and, NewCourtland Center for Transitions and Health, University of Pennsylvania School of Nursing, Philadelphia, PA, floresem@nursing.upenn.edu

Jo-Ana D. Chase, PhD, APRN-BC [Assistant Professor, Postdoctoral Fellow],
University of Missouri Sinclair School of Nursing, S343 Sinclair School of Nursing, Columbia, MO, 65211

T32NR009356, University of Pennsylvania School of Nursing, Philadelphia, PA,
chasejd@nursing.upenn.edu

Christine Bradway, PhD, RN, FAAN [Associate Professor of Gerontological Nursing],
CISA/Dept of Biobehavioral Health Sciences University of Pennsylvania School of Nursing Philadelphia, PA cwb@nursing.upenn.edu

Sheryl Potashnik, PhD, MPH [Project Manager], and
Decision Support: Optimizing Post-Acute Referrals and Effect on Patient Outcomes, University of Pennsylvania School of Nursing, Philadelphia, PA, slpotash@nursing.upenn.edu

Kathryn H. Bowles, PhD, RN, FAAN, FACMI [van Ameringen Professor in Nursing Excellence, Director of the Center for Integrative Science in Aging]
University of Pennsylvania School of Nursing, Vice President for Research and Director of the Center for Home Care Policy and Research, Visiting Nurse Service of New York, Claire M. Fagin School of Nursing, 418 Curie Boulevard, Philadelphia, PA 19104

Abstract

The purpose of this study was to explore what hospitalized patients would like to know about post-acute care (PAC) services to ultimately help them make an informed decision when offered PAC options. Thirty hospitalized adults 55 and older in a Northeastern U.S. academic medical center participated in a qualitative descriptive study with conventional content analysis as the analytical technique. Three themes emerged. Participants were interested in (1) receiving practical

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Kathryn H. Bowles, (Corresponding Author), bowles@nursing.upenn.edu.

information about the services, (2) understanding "how it relates to me", and (3) having opportunities to understand PAC options. Study findings inform clinicians about what information to include when discussing PAC options with older adults. Improving the quality of discharge planning discussions may better inform patient decision-making and as a result increase the numbers of patients who accept a plan of care that supports their recovery, meets their needs, and results in improved quality of life and fewer readmissions.

Keywords

hospitalized adults; decision making; discharge planning; post-acute care; qualitative methods

Introduction

In 2010 there were approximately 14-million hospital discharges for adults 65 years old and older (Centers for Disease Control and Prevention [CDC], 2012). Evidence has shown that after discharge older adults report adverse events, illness management difficulties and quality of life challenges (Forster, Murff, Peterson, Gandhi, & Bates, 2003; Holland, Mistiaen, & Bowles, 2011; Lough, 1996), and between 18-20% of Medicare beneficiaries are being readmitted to the hospital within 30-days post discharge (Gerhardt et al., 2013). Recent research shows that receiving care and support after discharge are effective in improving health outcomes and can delay placement in long term care for older patients whether received from traditional post-acute care settings such as skilled home care or inpatient rehabilitation, or newer transitional care or bridge models (Altfeld et al., 2012; Boling, 2009; Coleman, Parry, Chalmers, & Min, 2006; Feltner et al., 2014; Naylor et al., 1994, 1999; 2013; Watkins, Hall, & Kring, 2012).

Recent research has emerged to show that when offered PAC services, many patients simply refuse to participate in these programs. In a recent study conducted in two large academic medical centers in the Northeast, approximately 30% of hospitalized patients admitted to medical units, who were identified as needing a PAC referral by their care team, refused PAC services (Topaz et al., 2015). Furthermore, the authors found that these patients had two times higher odds of readmission within 30 days than patients who accepted and received services (Topaz et al., 2015).

Little is known about why a patient might refuse post-acute care and to our knowledge, there have been no studies that directly ask patients about what information would be beneficial for them to improve their understanding and decision-making ability regarding their PAC needs. Understanding patient information needs represents an important step in improving the quality of communication between the patient, discharge planner, and other members of the healthcare team (Forster et al., 2003; Horwitz et al., 2013). Targeted information may result in more informed discussions, which may increase the number of patients who accept, receive, and benefit from PAC services.

The aim of this study was to explore what hospitalized patients want to know about PAC services in order to make a more informed decision regarding their care post-discharge. Findings may inform the content delivered when clinicians educate patients and caregivers about PAC. The ultimate goal is to improve shared decision making discussions about PAC to increase the numbers of patients who accept a plan of care that supports their recovery, meets their needs, and results in improved quality of life and fewer readmissions.

Design and Methods

Design

A qualitative descriptive study design (Sandelowski, 2000) was selected to help illuminate participants' preferences regarding information they were interested in receiving during hospitalizations related to PAC services and to begin to build a knowledge base on this underexplored topic. Findings reported in this paper are from the qualitative analysis of participant responses to the question "When discussing options available to you for post hospital services, what would you like to know about your care and those services to help you make an informed decision?" This question was a part of a larger structured interview used in a qualitative descriptive study by the current authors with the overall aim of gaining a better understanding of patients' knowledge about PAC services and discharge decision making. During the individual interviews the research assistants (RAs) limited the discussion to the following traditional PAC service options typically offered to patients: home care, inpatient rehabilitation, skilled nursing facilities, nursing homes, and hospice. The mean time for the full interview was 46.5 minutes (range 25-115 minutes).

Setting and Participants

This study was conducted in seven medical-surgical units within a large, urban, academic medical center in the Northeastern United States. Patients were pre-screened for study eligibility by a hospital staff member using the electronic health record. Inclusion criteria were as follows: age 55 or older, and in need of PAC as determined by the Discharge Decision Support System (D2S2). The D2S2 is an evidenced based screening tool that identifies patients upon hospital admission who are likely to need PAC services (Bowles, et al., 2014a; Bowles, et al., 2014b). Exclusion criteria included the following: cognitively impaired (determined by documentation in the medical record or nurse report), unable to respond to interview questions, non-English speaking, and on do-not-resuscitate comfort care status (DNR-C). Participants were sampled for variation in gender, age, race, and the hospital unit they were admitted to (cardiac, medicine, and surgery).

Research assistants (RA) received a daily report listing patients age 55 or over and who were identified by the D2S2 as needing a PAC referral. The RAs then reviewed inclusion and exclusion criteria with the primary nurse of each potential participant. Thirty participants were consented and interviewed between July and October 2014. Pseudonyms for the participants are used in this paper.

Procedures

This study was approved by the University of Pennsylvania Institutional Review Board. Prior to data collection, written informed consent was obtained from all participants. Prior to conducting interviews with study participants, the four RAs involved in this study completed qualitative research training, including mock interviews, through the Mixed Methods

Research Lab at the University of Pennsylvania. RAs were trained to add specific probes, focused on types of PAC services a participant might consider (e.g., home care, inpatient rehabilitation, skilled nursing facility care, nursing home, and hospice care), and to facilitate and expand on participant responses as needed. Demographic characteristics were obtained directly from participants via a brief survey administered by the RAs. The sociodemographic data collected included gender, age, ethnic and racial background, highest level of education completed, insurance type, and self-rated health. RAs also collected primary diagnosis and co-morbid conditions (type and number) from the electronic medical record system. Each interview was audio-recorded and transcribed verbatim by an independent professional transcription service. All transcripts were compared to the audio files for accuracy by one author (EF) and one RA prior to beginning data analysis.

Coding and Data Analysis

The analytical technique for this study was a conventional content analysis (Hsieh & Shannon, 2005). This is a process that involves being immersed in the data and reading the data word by word to derive codes which are exact words that capture key thoughts. Codes are next sorted and organized into clusters based on their relationship to one another. Clusters, also referred to as categories, are then organized into themes (Elo & Kyngas, 2007; Graneheim & Lundman, 2003; Hsieh & Shannon, 2005).

Transcripts were uploaded into the software package Atlas.ti which was housed on a secure research drive (Scientific Software Development GmbH, version 7). The software was used to store and manage the data during the coding process. Three of the authors (JSS, RN, & EF) independently completed a first level coding of all transcripts and met to discuss initial impressions of the data, to organize the key words into meaningful clusters, and to develop a codebook of the identified categories and their definitions. The full team discussed the code book and made refinements. One author (RN) completed a second level coding and another author (JSS) completed an audit of all the coding. Further refinements were made after discussion and the full team met to discuss the themes that emerged.

Trustworthiness

The investigators incorporated three approaches to ensure trustworthiness of this qualitative study (Lincoln & Guba, 1985). First, investigators kept a detailed account of initial codes, categories, and final themes and developed a code book to account for decisions during ongoing data analysis (audit trail). Second, three separate investigators performed initial data analysis (investigator triangulation), followed by in-depth review and consensus from the entire team regarding final themes and overall study findings. Finally, a process of peer debriefing was facilitated by the Advanced Qualitative Collective, a group of faculty and pre- and post-doctoral students who meet regularly; this group of scholars who were not associated with the study engaged in a discussion with the investigators to address challenges and to review study findings. In addition, a thick description of the findings has been provided in this paper so that readers may make a conclusion on their own about the transferability of the findings.

Results

Participant characteristics

The participants were 50% female with a mean age of 70 (range, 55-91). Twenty participants were White-non-Hispanic (66%), nine identified as Black or African American-non-Hispanic, and one participant was Black or African American and Hispanic (33%). The sample was well educated with 70% of the participants having a post high school or greater education. In addition, 73.3% had Medicare coverage, and 76.6% rated their health as fair or poor. On average, participants experienced 7.6 comorbid conditions (range, 3-23; SD 4.4). All patients had different primary diagnoses (the exception was two participants with a diagnosis of sepsis) with 36.7% of the participants having a cardiovascular primary diagnoses while 20.0% had respiratory diagnoses. Additional details related to sociodemographic and clinical characteristics are found in Tables 1 and 2 respectively.

Three primary themes emerged after analysis of 30 participant responses to the question “When discussing options available to you for post hospital services, what would you like to know about your care and those services to help you make an informed decision?” Participants were interested in (1) receiving practical information about the services, (2) understanding “how it relates to me”, and (3) having opportunities to understand PAC options. Although most participants’ responses were focused on the three primary themes, four participants responded by saying, “I already know” due to their previous experiences with PAC services. This finding is also reported here as a secondary theme that emerged from the data.

Practical information about the services

Participants were very forthcoming in expressing their desire for practical information about potential PAC services so they could make informed decisions. Practical information included information about cost, extent of the service, quality rating and condition of the facility, and staff qualifications. The upfront financial cost of services was reported as being important, as well as specific information about insurance coverage (e.g., the type, length, and portion of services covered by their insurance plan). One participant, Marie, noted that she would want to know if her insurance would pay for it “because that’s the only way I could have the service”. Jim expressed that despite “pretty good” insurance, it would still be important for him to know if the service would be associated with any out-of-pocket expenses.

The extent of the services available was also of interest. As Tommy put it, “I want to know what they’re going to do, when they’re going to do it, who is going to do it and for how long.” Participants expressed wanting a healthcare provider to talk with them to give as much information as possible including pros and cons of the different available services and how long the services are “good for”. Findings regarding home care services focused on participants’ interest in specific information such as the number of days/week and time of day a provider would come to their home, the credentials and educational level of those providing care, and specifics about the type of care that would be delivered. As Margaret explained it is important to know: “Who is coming in and out of your home. You are sick there and maybe everybody is out for the day or something...I've got to get to know people before I let them come in my house like that nowadays."

For services other than home care (specifically inpatient rehabilitation, skilled nursing facility care, nursing home placement, and hospice), our findings showed that participants were interested in knowing more about facilities' reputations for quality of care provided and service ratings. In addition, when participants are considering placement in PAC services, they expressed an interest in the logistics of how a particular facility operates and how facility policies may impact the participant or their loved ones, for example, visiting hours.

"How it relates to me"

The theme "how it relates to me" included participants wanting information about the service expectations of them if enrolled, personal benefits they would receive, and how the services related to their own condition. Patients wanted to know what might be expected of them if they chose a certain PAC service, including what might be physically expected of them. For example, Carol said she would want to hear about expectations in terms of the "The dos and the do nots. The cans and can nots." Participants expressed a desire to have information tailored to them so that they would be able to determine personal benefits of receiving PAC services. As Joan put it: "how is it [receiving a service] going to make my life easier?" Furthermore, participants wanted to know more about their health condition and how a PAC service would specifically pertain to "my condition". One participant (Jerry) asked:

> "How is it going to benefit me as far as making me better from where I am right now? The ailment that I am at, or whatever, what can you explain to me that is going to make me, make it better for me?"

Opportunities to understand options

This theme included receiving clear information, both verbally and in written form, about services and having the ability to gather more information. Receiving clear information about services from providers was particularly important for participants who did not have any prior experience with PAC services, because they "don't know too much" about the services available. Anthony explained that people should be given clear information about PAC options because without prior knowledge about services they do not know what questions to ask providers.

In addition to receiving information in the hospital from providers about PAC options, participants also described wanting to gather their own information before making PAC decisions. For example, some reported an interest in doing their own research online and reading more about facilities or services that might be considered for PAC. Ann noted that she would want to gather more information by "talking to other people that maybe went to the same place. Usually it's better word by mouth instead of reading something that – or experiencing it yourself". Other participants also expressed an interest in visiting potential facilities to observe the environment and to have the ability to ask staff questions before making a decision.

I already know

Responses from four participants fell outside the three primary themes and were coded as: “I already know”. For example, Gladys responded to the interview question by saying “Nothing, because I already know the services”. Carol explained: “I know just about everything. I mean, I had diabetes for like over 30 years. So I know a lot of stuff”.

Discussion

We investigated the type of information hospitalized patients would like to know regarding PAC service options during their hospitalization by directly asking participants their opinions and ideas on this topic. The goal of our research was to begin to build a knowledge base as well as provide discharge planners, case managers and other providers with the kind of information patients stated they wanted in order to make more informed decisions about PAC services. We found that participants were interested in (1) receiving practical information about the services, (2) understanding “how it relates to me”, and (3) having opportunities to understand PAC options.

Many study participants expressed the need to know basic, practical information about PAC services, such as out-of-pocket costs, types of services provided, schedules of services, and facility ratings and rankings. Similar findings have been reported by Alexander, Casalino, and Meltzer (2003), in which 63% of participants in their study expressed a desire to discuss out-of-pocket costs. However, only 15% of the study participants actually reported having such conversations with their providers (Alexander et al., 2003). PAC facility rankings, services, and quality information are readily available, but only for nursing home and home health care. The Centers for Medicare and Medicaid (CMS) manages PAC comparison websites that provide consumer oriented information in the form of standardized, risk-adjusted quality report cards (CMS, 2015a; CMS, 2015b). These websites, which are regularly updated and based on national datasets, represent the most comprehensive tools provided by CMS to aid patients and discharge planners in choosing a PAC service. Nevertheless, Castle (2009) found that while 63% of discharge planners were aware of this widely available resource, only 38% actually used the website.

Participants in this study preferred PAC information tailored to their specific needs and conditions. Tailored information contributes to patients’ positive personal experiences in health transitions and decision-making (Giosa, Stolee, Dupuis, Mock, & Santi, 2014; Gladden, 2000). Information related to PAC options should be patient-centered and based on evidence, explaining how services will impact recovery or adaption to patients’ specific needs. For example, a comprehensive needs assessment during hospitalization could improve identification of relevant PAC services by providing a framework for tailoring information to patients’ needs (Graham, Ivey, & Neuhauser, 2009; Low et al., 2015). A tailored description of skilled services provided could then help patients see that services such as complex medication management, wound care, and physical therapy are beyond what they are prepared to perform for themselves, or what their caregivers are able to perform for them immediately following hospital discharge.

Past research supports the importance of providing patient-centered care across transitions in health care settings (Enderlin et al., 2013; Giosa et al., 2014). Patient-centered models for discharge planning may reduce rehospitalization and health care costs (Altfeld et. al., 2013; Coleman et al., 2004; Feltner et al., 2014; Naylor et al., 1994; Watkins et al., 2012). These models typically involve time limited patient follow-up after discharge, nurses or other individuals familiar with PAC services to facilitate navigation through the transition process, and communication and collaboration among providers and patients or caregivers across care transitions (Enderlin et al., 2013). Thus, these models exemplify consistent and personalized information exchange between providers and patients to enhance adaptive planning for patient-centered care.

Participants also have a need to understand their specific responsibilities while enrolled in a PAC service. A lack of clarity in patient roles in key aspects of PAC services may exist during conversations related to PAC services (Gladden, 2000; Toscan, Mairs, Hinton, Stolee, & InfoRehab Research Team, 2012). Clear information regarding specific roles and rights of patients in PAC services could increase a patient’s sense of empowerment and collaborative decision-making (Toscan et al., 2012). Although the participants in this study did not discuss caregivers, the roles of caregivers, family members, or other individuals in the patients’ social support network should also be explained (Toscan et al., 2012).

Our findings demonstrate that participants want to receive clear information from providers and discharge planners. Presenting clear information may involve adapting delivery strategies to patients’ needs. For example, limited levels of health literacy could impact receipt of clear information related to PAC services (Horwitz et al., 2013). An assessment of preferred learning strategies and provision of different options for information delivery, such as verbal or written instruction and video or interactive methods, could enhance the receipt of clear information for patients (Chugh et al., 2009). Furthermore, incorporating patients and caregivers early in the discharge planning process could increase the number of opportunities to hear and assimilate clear information on PAC options.

In addition to receiving clear information from providers and discharge planners, participants discussed using alternative sources of information to conduct their own research on PAC services. For example, participants mentioned using online resources. Older adults who use Internet and email services most often use these tools to research health related information (Keenan, 2009; Zickuhr & Madden, 2012). Therefore, providers and case managers may consider utilizing Internet platforms to share information with patients or providing links to resources that patients may use to gather more information about services.

Participants also expressed interest in talking to people who have had PAC services and visit a facility prior to making a decision. Although patients and caregivers or family members need adequate time to gather information from these alternative sources, approximately 30% of patients receive less than one day notice before discharge (Horwitz et al., 2013). Having time to educate, gather information and participate in shared decision-making takes time, and with 85% of older adults wanting either a collaborative or an active role in discharge planning decision-making, efficient approaches are needed (Popejoy, 2011). Discussions related to PAC options should begin in the outpatient setting, with providers encouraging patients to explore preferences and gather information related to PAC services prior to an actual acute event or planned admission. Hospital systems could utilize their volunteer workforce by pairing volunteers who had experienced a PAC service to patients with questions. Moreover, decision support interventions such as the D2S2 may help to identify and alert case managers upon admission as to which patients are likely to need PAC to start discharge planning processes and discussions early (Bowles, et al., 2014a; Bowles, et al., 2014b).

In our study, some participants were already familiar with PAC services. In these cases, patients must integrate prior knowledge with their current situation and with new information provided during discharge planning. Asking patients about prior experiences and knowledge related to PAC could improve tailoring of content, identifying misperceptions, confirming knowledge and sharing information among clinicians, case managers, and these patients.

Limitations

Although rigorous qualitative methods were applied throughout the study, the 30 participants were those of a convenience sample who were hospitalized and identified as likely needing PAC services in one academic medical center in the Northeastern United States and were all English speaking. All study participants were educated at least at the high school level. Study strengths included a diverse age range of participants, of different races, who had multiple comorbid conditions often seen in the clinical setting. Results are limited to the answers from one focused question about patients' information needs and the probes used by four different RAs to elicit detail may have varied.

Implications

Our findings suggest that patients need and want tailored information related to PAC services that focus on patient needs and conditions. Strategies to tailor PAC service information to patients' specific needs and conditions require engagement of patients and caregivers in shared dialogue. Clarifying patient and caregiver roles in PAC services, assessing patient knowledge, experiences, and preferred learning strategies related to PAC, and delivering tailored information are potential effective engagement strategies. Additionally, discharge planning discussions should occur early in the hospital stay to allow time for productive dialogue and information gathering.

We recommend future research that builds on this study. Future research might explore and compare diverse strategies for knowledge acquisition about PAC services among a heterogeneous sample of older adults and their caregivers. Moreover, studies are also needed to examine older adult's use of the Internet or web based interactive programs for PAC service information. Research is also needed to explore reasons why patients refuse PAC, develop new interventions to elicit patient preferences at the bedside, and evaluate the impact of supported decision-making on PAC referral acceptance rates and patient outcomes such as readmission.

Conclusions

This qualitative descriptive study has laid the ground work for building knowledge related to the type of information that patients want in order to make a more informed decision for selecting a PAC service. Participants were interested in receiving practical information about the services, understanding "how it relates to me", and having opportunities to understand PAC options. Our findings can assist clinicians in directing conversations regarding PAC services, and hopefully increase patients' understanding of what is being offered and the benefits to their care.

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Table 1

Socio-demographic characteristics of the sample (n = 30)

Age	
Mean (SD)	70 (9.9)
Range	55-91
Age Category, No. (%)	
55-64	8 (26.7)
65-74	14 (46.7)
75-84	4 (13.3)
85+	4 (13.3)
Female, No. (%)	15 (50.0)
Ethnic Background, No. (%)	
Not Hispanic or Latino	29 (96.7)
Racial Background, No. (%)	
White	20 (66.7)
Black or African American	10 (33.3)
Highest Grade Ever Attained, No. (%)	
Grade	5-81 (3.3)
High School Incomplete	3 (10.0)
High School Complete	5 (16.6)
Post HS/Business or Trade School	2 (6.7)
One to Three Years College	9 (30.0)
College Completed	6 (20.0)
Post Graduate College	4 (13.3)
Insurance, No. (%) [a]	
Medicare	22 (73.3)
Medicaid	5 (16.7)
Private Pay	15 (50.0)
Other	6 (20.0)
How would you rate your health at the present time? No. (%)	
Excellent	2 (6.7)
Good	5 (16.7)
Fair	16 (53.3)
Poor	7 (23.3)

[a] Participants could select more than one type of insurance, such as Medicare and Private Pay.

Table 2

Medical history of sample (n = 30)

Primary Diagnosis, No. (%)	
Cardiovascular	11 (36.7)
Respiratory	6 (20.0)
Sepsis	2 (6.7)
Vascular	2 (6.7)
Other	9 (30.0)
Number of Comorbid Conditions, No. (%)	
Mean (SD)	7.6 (4.4)
Range	3-23
Median	6
<5	5 (16.7)
5-10	19 (63.3)
11-15	4 (13.3)
>15	2 (6.7)