Understanding the Transition to Community Living After Discharge From an Acute Care Hospital: An Exploratory Study

Marie Gage, Joanne Valiant Cook, Karen Fryday-Field

Key Words: patient discharge • physical disabilities, occupational therapy

Objectives. This study was conducted to obtain patients' experiences in making the transition from an acute care hospital to their homes in the community.

Method. Data were gathered through group and telephone interviews with a volunteer sample of 27 discharged patients. Analysis involved two stages: categorization of shared themes and interpretation of individual occupational experiences.

Results. Informants described their experiences of transition in terms that were analytically categorized as Perceived Self-Efficacy, Resources, Dimensions of Occupation, and Environmental Constraints and Opportunities. Analysis of individual patient transcripts suggests the presence of an hierarchical ordering of desired occupations.

Conclusion. Understanding patients' perceptions of enabling and disabling experiences has implications for predischarge and postdischarge practice in occupational therapy.

Members of the occupational therapy department in a large, metropolitan, acute care hospital were becoming increasingly frustrated and concerned about the nature of their predischarge preparation. The therapists were regularly asked to conduct assessments and activities of daily living training 1 to 3 days before expected discharge. They had no resources for routine follow-up, and they had no evidence of the effectiveness of their practice in assisting patients to successfully manage their occupations (e.g., self-care, work, leisure) in the community. The therapists were particularly concerned about those patients whom they believed would experience some degree of ongoing physical disability. Therefore, an exploratory study was undertaken to discover how well patients felt prepared to function in the community. A better understanding of the process of reintegration into the community could be used to prepare predischarge protocols and to advocate for increased rehabilitation resources.

Literature Review

The few published articles that deal with community reintegration of persons with physical disabilities focus on the need to develop and monitor the success of reintegration programs and to ensure that the skills developed in rehabilitation are transferable to the community (Farzan, 1991; Johnston, 1991). Articles on physical illness and disability that are autobiographical or narrative pro-
vide insight into individual difficulties in reentering the community (e.g., Charmaz, 1991; Kaye, 1993; Kleinman, 1988; Murphy, 1990; Sacks, 1990).

A large American study of the health care experience from the perspective of medical and surgical patients in acute care facilities has shed light on patients’ experience during hospitalization and provides some insight into the needs of patients during reintegration into their community (Gerteis, Edgeman-Levitan, Daley, & Delbanco, 1993). This study has since been replicated with similar populations and findings in Canada (Charles et al., 1994) and the United Kingdom (Bruster et al., 1994).

Gerteis et al. (1993) identified seven dimensions of needs for these patients. The first six dimensions reflect needs during the hospital stay, whereas the final dimension deals with the reintegration phase. The dimensions are:

1. Respect for patients’ values, preferences, and expressed needs
2. Coordination and integration of care
3. Information, communication, and education
4. Physical comfort
5. Emotional support and alleviation of fear and anxiety
6. Involvement of family and friends
7. Transition and continuity

Although all the dimensions are important, the primary focus of our study was on the seventh dimension.

Gerteis et al. (1993) reported that patients and health care providers had different perspectives about what was important in a successful transition to community living. Health care providers emphasize management of the day of discharge, whereas patients’ concerns relate to the adjustment process once in the community. We designed the present study to explore the experiences and perspectives of patients at risk of ongoing disability during the transition from hospital to community living. Of particular interest was their perspective on the adequacy of their predischarge preparation.

Method

Informants

The names of all adult patients who had received occupational therapy services and had been discharged in the same 1-month period were drawn from the hospital’s computerized database. Only those of patients whose conditions were consistent with the possibility of ongoing physical disability were invited to participate in the group interviews at the hospital. Thirteen patients agreed to participate. A random sample of 11 patients were invited to participate in individual telephone interviews because they had indicated that they would like to take part in the study but were unable to leave their homes due to environmental barriers.

The 24 informants ranged in age from 20 to 86 years. Thirteen were women, and 11 were men. Their conditions included poststroke, hip fracture, cardiac dysfunction, shoulder fracture, vascular disorder, and arthritis.

Data Collection

There were three group interviews at the hospital at least 3 months after the informants’ discharge. Two groups ($n = 3, n = 4$) were composed of female informants and one group ($n = 6$) of male informants. The informant sample was divided in this manner to have some commonality in order to facilitate participation and self-disclosure (Krueger, 1994). The interviews primarily followed a semistructured interview guide (see Appendix), which is based on insights from the literature reviewed previously and on therapists’ concerns; however, if other issues arose, they were also pursued. Each group interview lasted 2 hours and was conducted by the first author.

The individual telephone interviews were conducted by two trained interviewers and varied in length from 10 min to 45 min. The telephone interviews were less wide ranging than the group discussions. All interviews were audiotaped and transcribed verbatim.

Data Analysis

The data analysis involved two stages. First, the transcripts were read and reread, and individual quotations were typed onto cards for sorting. Following both the analysis procedures described by Depoy and Gitlin (1994) and the “unitizing” (p. 344) and “categorizing” (p. 347) processes described by Lincoln and Guba (1985), the cards were first searched for units that shared similar content. These units were assigned broad categorical names. The categories were then examined to develop links or relationships between them and to determine common themes.

Second, the common themes were arranged and rearranged to determine whether there was a pattern to the collective grouping of informant experiences. The informants’ individual transcripts were reexamined to determine whether unique aspects to their description of their experiences existed.

Establishing Trustworthiness

Strategies to meet the criteria established by Lincoln and Guba (1985) for ensuring data credibility included the following:

1. Triangulation was partially achieved by using three
interviewers and by conducting both group and individual interviews. This tapped several sources, using slightly different methods and different investigators.

2. Peer debriefing was conducted with members of the occupational therapy department and researchers at the local university.

3. Member checking asked all informants to comment on the summary of results sent to them.

The recommended strategy of dense description to meet the criterion of transferability is limited by space requirements in journal-length articles. However, transferability is minimally addressed by inclusion of a brief description of the sample, direct quotations from the transcripts, and description of the interview process. The criteria of dependability and confirmability were met through modified audits of both the research process and the resulting product by a university researcher not involved in the data collection or analysis.

Results and Discussions

The data analysis revealed two models—the Elements of Transition Model and the Occupational Hierarchy Model—that promote enhanced understanding of reintegration into the community after an acute care hospital stay. Thus, the results, including analysis and implications for practice, will be presented in two separate sections that identify each model.

Elements of Transition Model

The data revealed two distinct time-bound and context-bound categories of experience: In-Hospital Experience and Transition to Living in the Community. Within these two categories, there were several themes that emerged, which are illustrated by selected quotations from the interviews. The pattern formed by individual elements is identified as the Elements of Transition Model.

In-Hospital Experience

After coding and recoding the data several times, those relating to experiences in the hospital were found to be consistent with the Gerteis et al.'s (1993) results. However, two new categories emerged: Being Believed In and Feeling Ready for Transition. Because the data related to the seven dimensions already defined by Gerteis et al. do not add new meaning, we will discuss only the two additional dimensions.

Being Believed In The informants appreciated the staff members who expressed a belief that the informants could master a difficult activity or the transition to their home. The confidence the staff members placed in them often stayed long after discharge:

There was [sic] a few people down there [in rehabilitation] that I specifically felt... it was on account of them that I got back to where I did. I really did. It was hard. They said, "Oh, you can do it. You can do it. I know you can." And if I did, I did come back.

I think it was... actually kind of a boost of confidence by the nurses and physio (physical therapist) and occupational therapists just saying that if they didn't think I could do it, I wouldn't be leaving.

Feeling Ready for Transition. The informants expressed a readiness for the transition phase when they had been told what they could or could not do after going home. However, this only made them feel prepared if they believed that they could function safely and successfully in their home environment or if adequate home care services and assistive devices had been arranged to compensate for those activities they felt unprepared or unable to do:

My physio and occupational therapists made sure that I had enough movement that, you know, I could somewhat help my husband in doing pivot transfers and things like that. So, yeah, I guess they did make sure that I was ready to go home, and it wasn't a push outside the hospital doors.

Interviewer: “Could we have done anything else to help you be ready?” Informant: “No, I don’t think so. I had everything I needed. It was just getting out there and doing it.”

When I say I didn’t get that much preparation, I guess ’cause there really isn’t a hell of a lot they can really do with like how you prepare someone when all of a sudden they can’t do anything. You know what I mean, barely feed yourself.

I was most fortunate. I was given a walker, a real good walker, with the wheels on it, and I could sit in the kitchen and do my work at the counter. I was given the shower, the thing you fit in the shower...the bar, and I had one of those raised toilets [seats], and that was absolutely a necessity.

Additionally, by having a number to call if necessary, informants were comfortable going home because they believed that they were not cut off from the staff members.

Transition to Living in the Community

The themes related to Transition to Living in the Community were subsumed within three major categories. These were: Resources, Dimensions of Occupation, and Environmental Constraints and Opportunities.

Resources: Intrapersonal. When informants spoke about how they managed to cope at home, they often discussed resources within themselves rather than things that had been done by health professionals to help them. They talked a great deal about the need to be internally resourceful in order to find new ways to do things that used to be easy:

Some of those kinds of things [not being able to carry things] was [sic] nasty for a long time, until I got a couple of stools. Then I could walk to the stool and reach for things. In other words, I had to invent my own.

They talked about success coming only through their personal determination to succeed.
If I set my mind to it, I can do it.

I try it, I tell you. I am a survivor. I'll try it, and if I find it is a little too tough, I'll leave it alone and try it again later.

On the other hand, health care professionals did not seem to pay enough attention to the informants' psychosocial needs. Informants described situations in which health care workers did an excellent job of preparing them to meet the physical demands of their life at home, but their emotional well-being was all but ignored. There were indications that the emotional adjustment to their altered lifestyles was tougher than the physical adjustment:

I was ready to go home, but psychologically I wasn't 'cause I was frightened. I was wondering how I was going to manage on my own. No, I don't think I was well enough prepared.

I thought my life was slipping away. Everything you wanted to do or thought you wanted, you couldn't do anything.

Resources: Interpersonal. The data suggest that these informants had been able to stay in their homes because of help from family members and friends. The informants depended on family members and friends for transportation in the community, shopping, personal care, and psychological support, for example: "Oh, I have no problem there [with transportation]. My daughter has got my car [to drive me places]." The informants were reluctant to bother health professionals with telephone calls and, thus, often relied on family members and friends for advice and information about their condition. One informant suggested that there should be a "help" line at the hospital so that patients would feel that it was appropriate to call with questions.

Resources: Services. Home care services played an equally important role in enabling these informants to live in their homes. The availability of homemaking services decreased the pressure to be fully independent immediately upon going home. As one informant put it: "The caseworker [home care] was just a pet, and she said, 'If you ever need anything, regardless of what it is, just don't hesitate to give us a call. We'll do all we can for you.'" The availability of rehabilitation services in the home enabled continued progress toward independence and was essential to the informants' well-being. Knowing that they could make further progress and become more independent was important to the informants' psychological adjustment.

On the less positive side, some informants believed that they needed more therapy because further progress seemed possible. Some patients experienced great frustration when they encountered situations that they were not prepared for and stated that they needed more information before and after discharge:

They didn't tell me how much movement I could make with my leg, what I could do, what I couldn't do. I phoned my doctor's secretary a couple of times and said I never had a broken hip before, and...I really don't know anybody that has, and none of my friends have, and I don't know what to expect. Should this be happening or that be happening?

They gave me this contraption [exercise sheet] at the hospital and they marked the ones to do, they did not tell me how many times a day to do them, or how long to keep them up, or whether to go on to others or not.

Many informants expressed frustration about the availability of services in the community. Although some of these comments were about the lack of availability of sufficient home care services, most of the frustration was about the inconvenience of public transit for persons with disabilities. Not being able to independently drive to a desired destination was a major loss. The impact of this loss was compounded by the inefficiencies of a transit system designed for persons with disabilities, which had to be booked and was often late.

Resources: Adaptive Devices and Techniques. For the most part, informants attributed their ability to cope in the home to themselves and the support of their family members, but they also recognized the important role played by the adaptive devices and procedures they learned in the hospital or through home care therapy services:

I mean it sounds funny now when you stop and think about it, but at the time, every little suggestion she [the occupational therapist] came up with was terrific.

You're all of a sudden thinking, "How am I going to do this?" But she [the occupational therapist] made it so much simpler because she had the information.

The large number of positive comments suggests that adaptive devices such as walkers, raised toilet seats, grab bars, and shower stools were an important factor in the successful transition home. Although the informants appreciated the additional independence offered by adaptive devices, they often found the cost prohibitive if they did not have a health plan that covered such expenses.

Dimensions of Occupation: The Importance of Doing. Of particular note was the importance the informants placed on being able to participate in occupations. The following informant comments illustrate the important function occupation plays for persons with disabilities (Meyer, 1922):

If you are able to keep your body busy, you don't have time to think about your illness.

I would keep my time occupied because if you don't keep this part [pointing to his head] of you going, it starts to go to sleep pretty quickly.

I would be happier if I had some little hobby that I could enjoy.
because...doing this work that I do now involves sitting too much.

The only thing I was wondering how I would manage would be in terms of keeping myself busy.

**Dimensions of Occupation: Recognizing Abilities and Limits.** The initial stage of the transition phase was filled with “tests” of the informants’ abilities. The informants gradually learned what they could safely accomplish and what they were no longer able to do for themselves. The initial few days were often filled with fear that they would not be able to cope, but gradually, as they found ways to accomplish what they needed, the fear lessened. One informant said:

I don’t know where my limits are, and I may see something that I should do. It’s like a nurse lifting a patient. That patient’s too heavy for them...they are gonna hurt their back, but there is no one else there to do it, and it’s something that you think should be done then, and I suppose that hits us all one way or another....So, I guess we have our fears about our abilities after something has happened to you, or your limits, or whatever.

**Dimensions of Occupation: Grieving the Loss of Independence and Control in Occupations.** All the informants described how they initially wanted life to be the way it used to be. Although home care services ensured safety in the home, they also led to a lack of privacy. One informant said: “If you have a homemaker everyday and all these things added to it...you don’t have any space for yourself.”

The loss most frequently grieved was that of the ability to drive or the loss of a driver’s license and the resultant need to depend on others to get where one wanted to go:

There was this brand new car in the garage, and I had to phone friends, anybody who could take me to appointments.

My car, my telephone, my pen, that’s my tool of trade. It’s my living. If I lose it....

**Environmental Constraints and Opportunities.** As the informants tried to resume their normal life activities, they reported encountering environmental barriers in their homes or the community. Stairs that had been no problem previously now prevented access to parts of their homes and sometimes necessitated moving to a new home. The most substantive proof of the stairs being a barrier to community access was the high proportion of potential informants who declined participation in this study because of an inability to exit their home unassisted. These patients were essentially “prisoners” in their homes, and they were not integrated into their community.

Access to the buildings in which the informants’ leisure activities took place was also sometimes a problem (e.g., stairs at the entrance to a church). Although many public buildings have been renovated for handicapped access, many continue to have barriers.

**The Elements of the Transition Model**

The several elements that emerged from the analysis of transition to community appeared to form a pattern. The foundation or base of successful, or unsuccessful, transition to the community was the informant’s perception of self-efficacy. In turn, self-efficacy influenced, and was influenced by, the following elements: the intrapersonal resources of the patient, the support of family members and friends, the availability and flexibility of home care services, the provision of adaptive services, the accessibility of desired environments, and the opportunities to be meaningfully engaged in chosen occupations (see Figure 1).

**Implications of the Elements of Transition Model for Practice**

The elements of transition and their interaction suggest a need to make changes to current acute care hospital practices if the transition home is to be smooth from the patient’s perspective. Informants felt ready to go home only when they believed that they were capable of doing what was expected of them in their homes. This suggests that the patients’ own perceptions of their abilities, that is perceived self-efficacy (Bandura, 1977), is more important than the perception of the health professionals. This phenomenon is consistent with a major tenet of self-efficacy theory: Perceived self-efficacy is highly correlated with actual performance. Thus, health care professionals may improve predischarge planning by evaluating the patient’s perceived self-efficacy for essential postdischarge activities (Gage, Noh, Polatajko, & Kaspar, 1994) in order to ensure that competent performance will occur after discharge.

Equalizing the importance of physical, psychosocial, and occupational adjustment may also ease the transition. If health professionals have assisted the patient in becoming fully independent in self-care, but the patient remains too depressed, afraid, or unable because of environmental barriers to function in his or her normal life roles outside the home, then only a limited outcome has been achieved. It is important to remember that health professionals are involved in a patient’s life for a brief time, whereas the patient and his or her significant others are left with the consequences of the health event for the rest of the patient’s life.

The development of strategies to help patients through the difficult time when they are learning new limits and are realizing that some meaningful activities will never be a part of their lives again can assist in their coping with the transition to community living. Although it is grati-
flying to learn that performance of occupations is important to persons with long-term disabilities, it is also disturbing to learn that these persons often struggle alone to find meaningful occupations that are within their abilities or within available, accessible environments.

Thus, it is important for health professionals to develop strategies that maximize each of these elements for every patient. Asking questions such as the following may result in a more successful transition:

• How can we ensure that this patient is confident that he or she is ready to function in the community?
• How can we tap the patient’s own internal resources?
• Do the patient’s family members and friends have all the information and support they will need to help the patient with a successful transition?
• Have the transitional services appropriate to meet the patient’s needs been activated (e.g., homemaking, transportation support, follow-up appointments, home care occupational therapy services)?
• Have we maximized the potential of adaptive devices and processes for this patient?
• Has the process of exploring meaningful occupations, when the patient is ready, been planned?

The Occupational Hierarchy Model
The second model that emerged from the data analysis was an occupational hierarchy of needs analogous to Maslow’s (1954) hierarchy of needs (see Figure 2). The second stage of analysis revealed that some informants were concerned about issues related to one level of need more so than other levels. Upon further examination of the data, the hierarchical categories emerged. The hierarchy was confirmed by reviewing the transcripts and noting the skills and deficits each informant expressed in relation to his or her particular needs and wants. In Maslow’s theory, all human needs are motivators of behavior. He divided human needs into five categories arranged hierarchically from the most basic to the most complex. He argued that needs at one level must be relatively well satisfied before the person turns to satisfaction of the next level of needs.

The occupational hierarchy of needs also has five levels. The first two are considered primary needs and the last three secondary. The labels attached to each need (but, not the hierarchical order) are derived from both the Occupational Therapy Guidelines for Client-Centred Practice (Canadian Association of Occupational Therapists, 1991) and Maslow’s (1954) hierarchy of needs. As in Maslow’s theory, the informants appeared to be motivated to satisfy needs at successive levels only after primary, lower level needs were met. The following is a description of each level of the occupational hierarchy.
**Self-Care**

Self-care refers to the person's ability to look after his or her basic personal needs, such as toileting, feeding, dressing, and grooming. Just as with Maslow's (1954) first two levels of needs, this level relates to one's ability to sustain the essential biological and physiological functions while protecting oneself from harm. Persons with disabilities do not have to be independent in these activities, they simply must have a strategy to address these basic needs.

**Home Management**

After self-care is no longer a major concern, the person's attention is turned to the accomplishment of home maintenance activities. This involves needs related to keeping the living environment in a safe and, to a lesser degree, aesthetically pleasing condition. Thus, housecleaning, gardening, tidying the home, and so forth are all activities that fall within this category. Again, independent action is not necessarily the goal. One must simply find a strategy that adequately meets his or her standards for the care of the living environment.

**Work**

For persons younger than retirement age, a need to return to paid employment emerges after the two primary needs have been adequately addressed. There appears to be an intense need to support oneself rather than accept social assistance or disability insurance payments. This level can sometimes be bypassed when the person believes that he or she has a socially acceptable reason not to work.

**Satisfying Leisure Pursuits**

After the person resolves the paid employment need, or if he or she is of retirement age, a strong desire to have some fun back in life emerges. The intense energy expended to resolve the issues faced at the first three levels leaves little room for doing things purely for pleasure. This does not mean that these persons never have fun, but having fun had not been a specific goal. They have been simply too busy getting through each day to plan leisure activities. For some persons, contributing in some meaningful way to the well-being of the world is what they always did in their leisure time; thus, the need to feel useful may arise at this stage.

**Self-Fulfillment**

After persons have balanced their need for self-care, home management, work, and fun, they begin to question whether they are realizing their full human potential. They begin to strive to develop their potential in whatever personally important direction they choose. This could involve self-development activities, use of creative talents, or a search for more challenging and fulfilling work.

It is important to note that although these needs are arranged largely hierarchically, they are not mutually exclusive. Issues related to the next need level begin to emerge before all the issues at the previous level have been resolved. The degree of concentration on the higher level needs is, however, lower than that for the essential needs in the lower level.

**Implications of the Occupational Hierarchy Model for Practice**

The conceptualization of an occupational hierarchy may mean that during an inpatient stay, providing the patient with skills that are transferable to the community may be impossible. One may only be able to intervene at one or two levels on the hierarchy at a time with any degree of success. Progress at higher levels may be elusive until issues at the lower levels are resolved to the satisfaction of the patient. Just because the occupational therapist has seen the patient dress in the hospital does not mean that the patient believes that he or she can dress independently in the home. Thus, it may be more important to ensure that further therapy is available to assist in the transition between each level of need than to attempt to fulfill all needs at the same time. Through the use of the occupational hierarchy, occupational therapists can advocate for the availability of services to coincide with the patients' emerging needs as they travel the full trajectory of their illness and adaptation to disability.

The occupational hierarchy has provided new understanding to an old problem at the hospital in which this study took place. The inpatient caseloads, coupled with short lengths of stay, have necessitated concentration on issues related to self-care and home management. For years, staff members have felt guilty about their inability to provide holistic care to patients. The staff members' understanding the occupational hierarchy has increased their comfort with practice. However, the lack of ade-
quate follow-up and community services to address the patients' higher level needs continues to be a concern.

Limitations
Given the small number of informants and the exploratory nature of the study, no generalizations can be made from our findings. However, as noted previously, the insights derived from the descriptions of our informants' experiences in the transition from hospital to community living were valuable in our hospital setting. The enhanced understanding of the hierarchical nature of recovery freed therapists of guilt when they were only able to address self-care needs in the inpatient phase. In addition, the need to enhance the patient's perceived self-efficacy for essential postdischarge activities became a stronger focus of the therapeutic intervention.

Directions for Future Research
The exploratory nature of this study led to the emergence of possible patterns of predischarge and postdischarge issues that merit further attention. For example, the relative effect and importance of the hypothesized elements of successful transition to the community need to be explored and standardized measures developed. Questions also arise in terms of the hypothesized hierarchy of occupations. That is, are the levels proposed here actually in order for all persons? The emphasis placed on the relative importance of the level of each occupation may be unique to each person.

Conclusion
Patients have much to tell us about their needs and wants in successfully returning to the community after hospital treatment. Occupational therapists' predischarge planning may be enhanced by an understanding of both the elements of successful transition and the level of occupational need the patient defines as primary. Attention to the preliminary findings of this exploratory study may contribute to both increased satisfaction with practice and improved outcomes for patients. ▲

Appendix
Focus Group Interview Guide

1. How have things gone for you since you left the hospital?
2. Looking back, how well were you prepared to cope with your life activities after discharge from the hospital?
   Who prepared you?
3. Did anyone ask whether you believed that you were ready to be discharged?
4. When you left the hospital, did you believe that you understood what the follow-up arrangements were?
5. Have you been faced with anything you cannot do that you would like to be able to do?
6. Are there things that you can physically handle but are afraid to attempt?
7. How have you dealt with the changes in your life that resulted from your illness?
8. What would have improved your degree of preparation? How could we have helped you prepare for discharge?
9. What information did you get that turned out to be useless?
10. What was the most useful piece of information you received?

References