ORIGINAL RESEARCH

Post-hospitalization transition to home: Patient perspectives of a personalized approach

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ABSTRACT

Objective: Successful transition from hospital to home for persons having multiple chronic illnesses is vital for improved health and reduction of hospital readmissions. This qualitative study was undertaken to explore patients' experiences with tailored care transition interventions in order to improve future interventions in a planned larger study.

Methods: Eighteen patients were interviewed either individually or in focus groups. Patients had previously completed a larger study that evaluated the impact of post-hospital discharge care transitions interventions, which were tailored to cognitive level and patient activation status. Data were analyzed using qualitative, thematic analysis techniques.

Results: The overarching theme identified as a result of the qualitative interviews was: Tailoring Interventions to Address the Complexity of Multiple Chronic Illnesses. It included Checking in or checking out: Patient activation and self-management of chronic illness; Increasing complexity: Management of medications for chronic illness; and Paving a path through complexity with caring. These themes were found in all participants, across all groups of the interventions.

Conclusions: Tailored interventions, which included individual assessment of needs and development and implementation of a tailored self-management plan, were viewed as effective by patients for self-management of chronic illness, particularly medication reconciliation and weekly goal setting.

Key Words: Care transition, Patient activation, Self-care, Qualitative research

1. INTRODUCTION

An estimated half of all adults living in the United States have been diagnosed with one or more chronic health conditions and increasing rates of chronic illness are associated with higher rates of hospitalization and readmission to the hospital within 30 days of discharge.[1] The cost of readmission is significant, both in dollars and burden to patients and their families. Medicare beneficiaries are experiencing record numbers of transitions between health care settings.[2] These data demonstrate that care during transitions could be improved, both in efficacy and efficiency. Care transition models that deliver standardized discharge planning strategies may be efficient; however, these methods do not consider the individual needs of patients (such as patient cognition and activation) and resources or care needed after discharge and thus may be over or under dosed for efficacy with improving patient outcomes for patients with chronic illness.[3,4] More information from the patient's perspective is needed to evaluate the effectiveness of tailored post-hospitalization transition-to-home programs.

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This study was undertaken as the qualitative arm of a larger pilot study, which was designed to tailor the dosage of intervention needed based on level of cognition and patient activation in order to improve transitional care of patients and their caregivers through provision of a home-based care transitions intervention (HBCTI) program. The program was designed to reduce 30-day hospital readmission rates for patients with multiple chronic illnesses. For this study, patients were interviewed following their completion of the tailored interventions. The purpose of this qualitative, descriptive study was to explore patients' experiences with the tailored care transition interventions in order to improve future tailoring for interventions in a planned larger study.

Three primary care transition models were utilized to form the basis of interventions used in the larger study: Naylor's Transitional Care Model,[5] Coleman's Care Transitions Intervention,[6] and Project RED (Re-Engineered Discharge).[7] Self-management support programs have demonstrated effectiveness in improving patient outcomes during the transition to home process. In general, successful programs use the following strategies to improve outcomes and reduce hospital re-admission rates:

- Implement tailored interventional strategies specific to the patients' needs and their condition(s).[3, 4, 8, 9]
- Focus on behavioral interventions with goal setting in addition to cognitive interventions.[3, 8, 10–12]

Tailoring of care begins with an informed assessment of the patient, development of a self-management plan specific to the patient, and implementation of the tailored plan in a meaningful and effective manner.[13] Patients need to be prepared to take an active role in the management of their own health; this is often described as patient activation. Patients who are highly activated are motivated to learn about their illness and develop strategies to manage symptoms; in other words, the chronic condition "has their attention". Patients with low activation are less motivated, more passive regarding self-management, and more likely to experience negative emotions.[3, 14] High levels of patient activation have been significantly correlated with improved health indicators,[15] health-seeking behaviors,[15] improved self-management behaviors,[3, 12] and reduced use of health care resources.[15, 16] Methods demonstrated to improve patient activation include increasing the quantity and quality of time spent with the health care provider[17] and use of a tailored approach during self-management education.[8]

Cognition, or the ability to learn, comprehend, and apply new information, is critical to the success of self-management of chronic illness. Patients need to understand the purpose of prescribed therapies in order to regain or maintain health and independence. Patients often lack the knowledge and confidence necessary to correctly comprehend post-hospitalization discharge instructions.[18, 19] Unplanned hospital readmission rates have been reported as higher for persons having lower cognitive levels.[18] Patients having lower cognition levels may not recognize or report medication adverse effects, which may further lead to increased morbidity and health care costs.[20]

2. METHODS

2.1 Design

The portion of the study reported here was guided by descriptive research methods, which are well suited to understand the meaning of an experience from the perspective of the persons having that experience, such as the tailored interventions in this study. Focus groups and individual interviews were used to collect data regarding the patient experiences, as both provide understanding of individual's perceptions and preferences of the tailored interventions being studied.[21, 22]

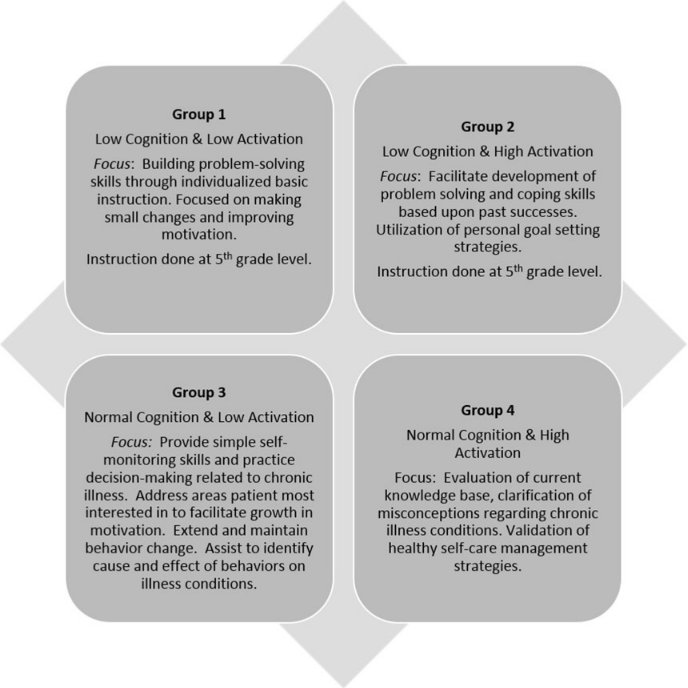
2.2 Patient population

Patients who had received tailored interventions were telephoned by one of the investigators of this sub study who had not been involved in the larger study. They were asked to participate in either a focus group or individual interview to help understand the intervention, that is, to discuss what was important about the intervention, how it might be improved, and the usefulness of the intervention. All patients were assured of confidentiality and that their individual remarks would only be shared in a way that would not identify them.

Patients in this study were part of a larger intervention study designed to reduce hospital readmission. All those in the study were discharged from a large medical center in the Midwest, had three or more chronic illnesses, and were able to hear, speak, and read English. Patients having dementia were excluded from study participation. Patients in the larger study had been assigned to one of four groups based on their level of cognition and patient activation status.

Patients were then randomly assigned to either receive interventions tailored to their cognition and activation or to the control group receiving usual discharge care and follow-up. Cognition was assessed using the Montreal Cognitive Assessment tool (MoCA);[23] Patients scoring below 17 were considered to have dementia and excluded, patients scoring 17-26 as having low cognition, and those scoring above 26 as having normal cognition. Patient activation was assessed using the Patient Activation Measure (PAM).[11] Patients scoring a level 1 or 2 of the PAM were considered to have low patient activation; levels 3 or 4 were designated high activation levels.

The four intervention groups were: Group 1 (low activation and low cognition level), Group 2 (high activation and low cognition level), Group 3 (low activation and normal cognition level), and Group 4 (high activation and normal cognition level). The interventions lasted for 1 to 8 weeks immediately following hospital discharge, depending on group assignment. The four primary components of the interventions included: medication reconciliation, mutual goal setting/coaching, written instruction, and home visits or telephone follow-up. Group 1 received three home visits from an advanced practice registered nurse-nurse practitioner (APRN-NP) and eight weekly visits from a certified nursing assistant (CNA). Group 2 received three home visits from an APRN-NP, two CNA visits during weeks 1, 3, and 5 and CNA phone follow up calls during weeks 2, 4, 6 and 7. Group 3 received a home visit from an RN coach during week 1 and follow up phone calls during weeks 2, 3 and 4. Group 4 received written and verbal patient educational materials prior to discharge and a follow-up phone call by an RN coach within 1 week of discharge. Tailored interventions are further described in Figure 1. Figure 2 describes the roles of each health care team member (APRN-NP, RN Coach, and CNA).



Group 1

Low Cognition & Low Activation

Focus: Building problem-solving skills through individualized basic instruction. Focused on making small changes and improving motivation.

Instruction done at 5th grade level.

Group 2

Low Cognition & High Activation

Focus: Facilitate development of problem solving and coping skills based upon past successes. Utilization of personal goal setting strategies.

Instruction done at 5th grade level.

Group 3

Normal Cognition & Low Activation

Focus: Provide simple self-monitoring skills and practice decision-making related to chronic illness. Address areas patient most interested in to facilitate growth in motivation. Extend and maintain behavior change. Assist to identify cause and effect of behaviors on illness conditions.

Group 4

Normal Cognition & High Activation

Focus: Evaluation of current knowledge base, clarification of misconceptions regarding chronic illness conditions. Validation of healthy self-care management strategies.

Figure 1. Sample tailored interventions by group assignment

Description of type of tailored intervention based upon group assignment. All patients received basic instruction on medications (including medication reconciliation), diet, exercise, and red-flags of worsening condition. Low cognition = Score of 17-26 on Montreal Cognitive Assessment (MoCA);[23] Normal Cognition ≥ 26 on MoCA. Low activation = Level 1 or 2 on Patient Activation Measure (PAM);[11] High activation = Level 3 or 4 on the PAM.

APRN-NP and RN Coach

- Written, verbal, and hands-on instruction regarding medications, diet, exercise, red-flags of worsening condition
- Instruct in self-monitoring skills levelled to patient ability
- Encourage active participation in self-management of care
- Reinforcement of positive changes to promote health
- Assist with personalized goal setting and evaluation of effectiveness
- Ongoing evaluation of progress
- Advised and directed CNA as needed during home visits and follow-up phone calls

CNA

- Provide hands-on assistance with personal care (ADLs, in-home exercises)
- Report patient status to APRN-NP or RN Coach

Figure 2. Provider roles and responsibilities

Roles and responsibilities for health care team members. Level and intensity of interventions varied based upon group assignment. APRN-NP = Advanced practice registered nurse-nurse practitioner. RN = Registered Nurse. CNA = Certified Nursing Assistant.

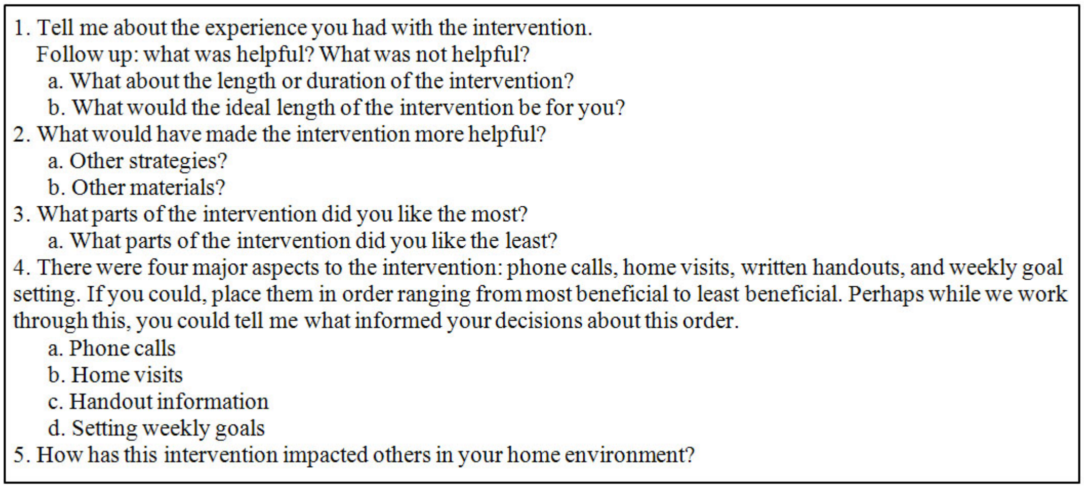
2.3 Data collection

All patients completing tailored interventions in the larger study (n = 107) were eligible to participate in the qualitative arm of the study. Following Institutional Review Board (IRB) approval, eligible patients were contacted by telephone and invited to participate in the qualitative arm of the study. Patients were contacted sequentially according to the order in which they completed the larger study. Verbal consent for the interviews was obtained since the IRB deemed the study to be minimal risk. Data collection began with a scheduled focus group. Patients who were unable to attend the focus group were interviewed individually in person or over the telephone (according to patient's stated preference) after completion of the focus group meetings. Interviews continued until no new information was shared, that is, until data saturation was achieved.

2.4 Interviews

Eighteen patients agreed to participate in the qualitative arm of the study. All patients were asked to describe their experience with the tailored interventions, including what was helpful and what was not helpful. In addition, they were asked for suggestions for improving the interventions. Patients also talked about how the tailored intervention benefited them, the parts of the intervention they liked most and least, and how the interventions affected their understanding of their chronic disease. Finally, they were asked how the interventions affected others in their homes. All patients spontaneously talked about their chronic illnesses and how these affected their lives. The interview questions used for all data collection (focus group, interviews, and phone interviews) are in Figure 3.

All interviews were audio recorded and transcribed verbatim. Transcripts were analyzed by two researchers with experience with qualitative analysis using thematic analysis techniques as described by Braun and Clarke.[24] Transcripts were read thoroughly several times to get an understanding of the whole. They were then examined line by line, and important phrases were underlined and labeled in the margins. Labels were sorted and grouped and then discussed and consolidated into themes. The two researchers discussed the themes until agreement was reached. Themes were compared across groups from the initial tailored intervention as well as across type of interview (focus group, individual interview, and telephone interviews). No differences were found in any of these comparisons.



1. Tell me about the experience you had with the intervention.
   Follow up: what was helpful? What was not helpful?
    a. What about the length or duration of the intervention?
    b. What would the ideal length of the intervention be for you?
2. What would have made the intervention more helpful?
    a. Other strategies?
    b. Other materials?
3. What parts of the intervention did you like the most?
    a. What parts of the intervention did you like the least?
4. There were four major aspects to the intervention: phone calls, home visits, written handouts, and weekly goal setting. If you could, place them in order ranging from most beneficial to least beneficial. Perhaps while we work through this, you could tell me what informed your decisions about this order.
    a. Phone calls
    b. Home visits
    c. Handout information
    d. Setting weekly goals
5. How has this intervention impacted others in your home environment?

Figure 3. Structured interview guide

2.5 Sample

A total of 18 patients were interviewed. One focus group of 7 patients was held at the hospital from which the patients had been discharged. Two facilitators, who were skilled in qualitative interviewing and not involved in intervention delivery, guided these discussions. One facilitator took notes in addition to the audio recording. In addition, two individual interviews were held at the hospital, and another 9 individuals were interviewed by telephone. One of the facilitators who had led the focus group conducted the individual and telephone interviews.

In general, the patients interviewed were similar to those of the larger parent groups, with the exception of the groups with lower cognition levels (Groups 1 and 2). Group 1 (M = 10 ± 1.0) and Group 2 (M = 4.5 ± 1.1) had a wider variation in the number of comorbidities than patients in the larger parent study (parent study group 1 [M = 7 ± 2.1]; parent group 2 [M = 7.3 ± 3.6]). Demographic characteristics of those interviewed are in Table 1. The five most common comorbidities across all groups included hypertension, hyperlipidemia, osteoarthritis, diabetes mellitus, and obstructive sleep apnea. Of note, patients in Group 1 (low cognition/low activation) had more comorbidities (M = 10 ± 1.0) than patients in the other interviewed groups; patients in Group 4 (normal cognition/high activation) were more highly educated than patients in the other interviewed groups (M = 15 ± 3.5).

3. RESULTS

3.1 Theme: Tailoring interventions to address the complexity of multiple chronic illnesses

3.1.1 *Checking in or checking out: Patient activation and self-management of chronic illness*

All patients had been diagnosed with three or more chronic illnesses in order to participate in the study. Throughout the interviews, patients reported repeated hospitalizations for a variety of both acute and chronic illnesses. Varying levels of patient activation behaviors were also described. Some patients described self-management in a matter-of-fact manner, not fully engaging with the lifestyle changes needed for effective self-care. One patient reported, "So it's something I think I am going to have to live with. . . I will just live on medication to try and control it." Other patients reported a sense of being overwhelmed with the burden of multiple chronic illnesses and coped with this complexity by being selective with self-management, developing a more passive approach to their illnesses. One patient shared the following: "Trust me, you get to a certain age, there is so many things. I think if you were to turn around and question everything you would be busy all the time."

Others verbalized a more proactive management style to chronic illness. This was seemingly unrelated to the severity of disability. One example was a patient, audibly dyspenic during the interview, who reported prioritizing exercise in order to manage his symptoms and disability:

> I have severe emphysema and I take my own blood pressure and temperature and that sort of thing so I monitor that myself. . . I have had my nap and I have done my exercising today so I am in pretty good shape right now. . . they are both important. The exercising I think is probably more important than the nap.

Patients consistently described living with chronic illness as a life-changing event. Patients described the tailored interventions as assisting them to understand their illness and how to reduce the worsening or severity of their condition. For example:

> I found that I got information from the people that came to the house that I really didn't have it in my brain, I didn't know what high blood pressure was and so I wrote down those things that give me a guideline to go by and they helped me with different approaches.

The tailored interventions helped patients to navigate through the life changes required by their multiple chronic illnesses.

3.1.2 *Increasing complexity: Management of medications for chronic illness*

Patients reported feeling challenged to understand and safely manage their complex medication regimens. Tailored interventions included medication-related verbal instructions, ongoing medication reconciliation activities, and written information about their prescribed medications. These were well-received by patients:

> Yeah they went over the medicines a lot with me to help keep that in my mind, what they were for. . . I had six special medications that the doctor prescribed. . . some other ones that they sort of prescribed, but there is six main ones because I have arthritis and then I have stuff for my indigestion and so you know I have several things going that I need medication for. . . and the nice thing about the handout was that you can go back to it. The other day I was thinking about one of the medications so I went and looked it up on the list and it has just a small explanation but. . . that was enough to satisfy your mind.

Several patients reported near-miss events associated with mismanagement of medications that occurred prior to study participation:

> One [evening] I had taken my night medicine and [I live] a block and a half from the store so I figure I would hurry up get down to the store and get my meds picked up, I parked right in front of the store, that is the last I knew. Three hours later the people in the store are knocking on my window, "ma"am wake up, wake up we are going to call the police on you if you don't leave. I was so embarrassed. Yeah I didn't know my medicine kicked in that quick.

Patients consistently reported that medication instruction, provided in a repeated manner, improved their understanding and correct use of prescribed medications.

3.1.3 *Paving a path through complexity with caring*

Patients consistently reported feeling a genuine sense of caring during the phone calls and home visits involved with the tailored interventions. Patients felt supported and cared for, that their needs and concerns were important to the nurses. This perspective was summarized well by one patient, "They made sure I knew exactly why I was taking every one of my medications, if I was taking them, and they were concerned how I was feeling in general. . . just really encouraging." Another patient reflected, “I had been in the hospital three times that month and I was pretty excited and it was almost like somebody cared about me enough to come check up on me”, indicating the nurse served as a source of social support.

Patients found great value in the weekly goal setting that occurred as a part of the home visits, finding the activity both motivational and empowering:

> I thought the goals we set [in the tailored interventions] was one of the best for me. We would set a goal as what I would do, they gave me some exercises and things to actually do on my own and that was really very helpful to me.

Other patients described goal setting as a form of accountability, for example, “You knew they were going to come, you better be doing what you set for a goal.” Patients viewed progressive goal setting as an effective way to decrease the level of disability associated with their chronic illnesses.

One of the interview questions asked patients for suggestions to make the interventions more helpful. Patients had few suggestions to contribute. Most patients stated, “Nothing.” One patient stated a need for more home visits, and one other patient said more phone calls would have been helpful. Overall, patients stated satisfaction with the intervention delivery as designed.

Table 1. Demographic characteristics of patients

	Mean SD (range)	**Group 1 Low Cognition Low Activation**	**Group 2 Low Cognition High Activation**	**Group 3 Normal Cognition Low Activation**	**Group 4 Normal Cognition High Activation**
Total number	18	3	6	5	4
Number interviewed					
Focus group	7	2	3	2	0
Individual Interviews	2	0	1	1	0
Telephone Interview	9	1	2	2	4
Gender					
M	8	0	2	5	1
F	10	3	4	0	3
Mean age	65 ± 17 (32-88)	61 ± 16 (52-80)	73 ± 13 (52-88)	55 ± 11 (39-66)	67 ± 25.7 (32-88)
Employed for Wage	9	2	4	1	2
Marital Status					
Married	9	1	3	3	2
Single	2	1	0	1	0
Widowed	3	0	2	0	1
Divorced	4	1	1	1	1
Education	13 ± 2.4 (9-18)	12 ± 1.5 (10-13)	12 ± 2.2 (9-16)	13 ± 1.0 (12-14)	15 ± 3.5 (12-18)
Number of Comorbidities	6 ± 2.5 (3-11)	10 ± 1.0 (9-11)	4.5 ± 1.1 (3-6)	5 ± 1.9 (3-8)	7 ± 2.1 (5-9)

4. DISCUSSION

Statements made during focus group and individual interviews demonstrated patients felt positively about their experiences with the tailored interventions. Patients in Groups 1, 2 and 3 verbalized satisfaction with home visits and medication instruction. Patients in Group 4, who received written materials and one telephone follow-up call by the nurse, also expressed satisfaction with the dosing of intervention they received. Patients felt supported by the health care team as they worked toward effective self-management of living with the complexity of multiple chronic illness conditions. No differences were noted in patient responses to interview questions across the format or type of interview structure (focus group, individual interview, or telephone interview). Themes did not vary by group in which the patients were assigned for the tailored intervention. Patients in Group 1 having low activation/low cognition as well as the greatest number of comorbidities, were at (arguably) the greatest risk for unplanned re-hospitalization. Tailored interventions provided in the study were described as meaningful and helpful by patients, regardless of group assignment, which supports that interventions were appropriately tailored to the needs of each individual patient irrespective of group assignment.

Patients in the focus groups and interviews included persons with varying levels of activation and cognition. Patients received different types and dosage of interventions; this resulted in rich conversation during the focus group interview as patients described and defended the appropriateness of the tailored interventions they received.

It is important for nurses working with patients at discharge to help with goal setting and teaching self-management skills. Rather than tailoring intervention type or frequency to specific type of chronic illness or illness severity, as had been done in previous research, this study tailored delivery of interventions based upon estimation of the patient's cognition and activation status. Previous studies have examined the impact of interventions tailored to type of chronic illness[25,26] or disease severity.[27] Patients in all four groups reported satisfaction with the type and frequency of interventions they received. Patients in Group 4 had a higher level of education than those in Groups 1 to 3; written materials and one follow up telephone call was sufficient from their perspective. Patients in the other groups received interventions spanning a longer duration, allowing them to fully comprehend and assimilate the necessary changes into their lifestyle, with which they expressed great satisfaction. Patients in Group 1 (low cognition/low activation) had on average significantly more comorbidities and reported satisfaction with the dose of their intervention. Patients having low cognition/low activation and multiple comorbidities may be at greater risk for unplanned hospital readmission. Home visits with medication instruction and medication reconciliation were effective for this group. Written materials and a single telephone call alone may not have met the needs of patients having lower than normal levels of cognition or activation.

Medication instruction and reconciliation activities with the nurse were viewed as particularly helpful by patients. Medication reconciliation during care transitions has demonstrated effectiveness in prevention of serious medication errors in multiple studies.[19,28,29] These qualitative data support findings from the literature. Descriptions of near-miss events due to medication mismanagement demonstrated the patients' awareness of the importance of taking medications correctly. The ongoing nature of medication coaching and reconciliation activities used in this study was intended to promote medication adherence as one method of reducing unplanned hospitalizations. Patients affirmed the importance of this activity as critical to effective medication self-management.

Mutual goal setting, individualized to each patient and their situation, was identified by patients as a critical element in their post-hospital transition to home. Patients, and caregivers when available, were provided individualized health coaching with goal setting with each visit. Coaching and goal setting have demonstrated success in increasing patient activation levels.[8,30,31] Patients described the goal setting as improving their accountability for their own recovery and the sense of accomplishment which ensued upon attainment of the goal. This is an important component for teaching self-management skills to patients.[32]

Limitations of the study include the convenience sampling; however, despite this limitation, 15% of eligible patients participated in the study, and patients included persons from each of the four tailored intervention groups. Patients were invited to attend focus group or individual interviews based upon their own schedule and convenience. Reasons for participation in focus groups *vs.* telephone interviews were not disclosed during the discussion. Choice of type of interview may have been influenced by cognitive level, work status, or other unknown causes. This may have influenced the study findings. Other limitations include small sample size which limits the generalizability of the findings. Saturation of data was achieved, and the findings supported the effectiveness of the tailoring of interventions for patients in the study as they moved toward their self-management of chronic illnesses. Further research is needed to more fully refine and develop effective tailored interventions to reduce hospital readmission for patients with chronic illnesses.

5. CONCLUSIONS

Patients described satisfaction with the tailored interventions, and found two major components of the tailored interventions, medication reconciliation and weekly goal setting, as particularly helpful. The findings from these qualitative data support the fidelity of the intervention components delivered in the parent study: medication reconciliation, mutual goal setting/coaching, written instruction, and home visits or telephone follow-up. Patients indicating the importance of these components support the need to include these components in care transition programs. Findings from this study also support the notion that not all care transition programs should be the same and individual factors such as cognition and activations can be used to allocate resources and dosage of planned interventions. Rich descriptions of the patient experience with the tailored interventions provide support for the effectiveness of tailoring post-hospital care to cognition and activation levels. Qualitative data from this substudy support the need for tailoring interventions strategies by groups, as was the design of the larger parent study. This provides a bigger picture approach to the study of care transition for chronically ill patients. Future research should also address the other factors that predict patient activation and cognitions that should be included in tailoring the care transition programs. For example, does educational level influence patient activation or do certain comorbidities impact cognition more than others? More research in this area could help us better design tailored strategies for care transition programs.

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CONFLICTS OF INTEREST DISCLOSURE

The authors declare that there is no conflict of interest.

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