



October 2020

Patient Activation and Engagement (PAE): Guidelines for Acute Care Occupational Therapy Practice

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Recommended Citation

Moua, K. (2020). Patient Activation and Engagement (PAE): Guidelines for Acute Care Occupational Therapy Practice. *The Open Journal of Occupational Therapy*, 8(4), 1-11. <https://doi.org/10.15453/2168-6408.1716>

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Patient Activation and Engagement (PAE): Guidelines for Acute Care Occupational Therapy Practice

Abstract

This paper provides a set of guidelines for occupational therapists practicing “patient activation” and “patient engagement” approaches in the acute care hospital setting. Patient activation and engagement (PAE) has gained attention in the health care setting as the new effective intervention. Occupational therapists create client-centered goals and treatment plans in alignment with PAE approaches in the health care system but barriers continue to exist in practice settings that prevent appropriate implementation of such techniques. This paper presents evidence that an occupational therapist’s role should not be limited to the assessment of a client’s independence with activities of daily living in acute care hospital settings but should also involve being an active leader for the implementation for PAE interventions. As PAE interventions become widely implemented and create more role opportunities in acute care hospitals, the future of occupational therapy’s role cannot be simply left behind on the assessment of activities of daily living. The objectives of this paper are to introduce (a) assessments that measure both patient activation and patient engagement, (b) literature supporting the relationship between patient activation and patient health behaviors, and (c) clinical variables associated with a patient’s engagement levels.

Comments

The authors report no potential conflicts of interest.

Keywords

acute care, occupational therapy, patient activation, patient engagement, self-management

Credentials Display

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DOI: 10.15453/2168-6408.1716

Clients in acute care hospital settings who were readmitted in 30 days stayed 12.6 days longer and had approximately 50% higher 1-year costs than those not readmitted (Zheng et al., 2019). Jack et al. (2009) conducted a randomized trial evaluating a standardized discharge plan that decreased hospital use within 30 days of discharge by approximately one-third with an intervention that involved comprehensive discharge planning, postdischarge reinforcement, and client-centered education. The Affordable Care Act (ACA) emphasizes the need to expand access to health insurance, decrease health care costs, improve the delivery of client care, and shift toward a practice model of client-centered care. Three key provisions of the ACA were developed as a result of the dire need for client-centered care. First, the Centers for Medicare and Medicaid directly linked Medicare reimbursements with client satisfaction measured by patient reported outcome measures focused on (a) access to care, (b) provider communication, (c) coordination of care, (d) shared decision-making, and (e) perception of the office staff (Reineck & Kahn, 2013). Second, accountable care organizations were developed to manage the full continuum of care by holding health care systems accountable and incentivized for the overall costs and quality of care for clients in the domains of client and caregiver experience, care coordination, client safety, preventive health, and the identification of at risk populations (Centers for Medicare & Medicaid Services, 2011). And third, the attention of health care providers shifted toward the Care Model, an evidence-based framework promoting the delivery of safe, effective, and collaborative care to clients that highlighted the practice of patient activation and engagement (PAE); two key elements employed to increase quality of care and improve health outcomes (Koh et al., 2013).

PAE has gained attention as an effective intervention to decrease rehospitalization, improve adherence with positive client health behaviors, and promote the practice of client-centered care (Hibbard & Greene, 2013; Hibbard et al., 2013; Mitchell et al., 2014). The knowledge, skills, confidence, and onus to manage one's health and health care needs and to understand one's role in the care process is known as patient activation. Although several conceptualizations of the term patient engagement have been offered in the literature, the most popular and accepted definition is understood as a co-constructed relational process between the practitioner and client that involves a process of gradual connection between the two parties (Bright et al., 2015).

Attaining high levels of activation and engagement often begins with the active participation of clients in the health care process and client-centered care. In occupational therapy, client-centered care has foundationally been an integrated value and fundamental element. Occupational therapists historically have given clients an active role in the therapeutic process, created meaningful client-centered goals, and taught self-management strategies to their clients. A growing body of literature has supported the relationship between more activated and engaged clients and improved patient reported outcome measures as well as functional outcomes in inpatient rehabilitation settings; however, the research remains sparse in acute care hospital settings (Kringler et al., 2018; Lenze et al., 2004a; Paolucci et al., 2012). Despite the growing evidence influenced by health care policies focusing on PAE, health care professionals continue to have a limited understanding of PAE and treatment approaches in alignment with PAE techniques (Mishra et al., 2018). As attention is given to the client to become more involved in their own care, occupational therapists are expected as care providers to facilitate clients' knowledge, skills, and confidence to manage their own health through a co-constructed relationship in the acute care hospital setting.

The purpose of this paper is to provide occupational therapists working in the acute care hospital setting with guidelines for practicing PAE approaches and strategies to promote higher levels of

activation and engagement during the therapeutic process. The objectives are to provide an overview of (a) assessments measuring PAE, (b) the relationship between activation levels and health behaviors, and (c) clinical variables predictive of engagement levels.

Measuring PAE

Five instruments are introduced below that have established psychometric properties in a variety of populations that measure PAE. See references for more specific details about established reliability and validity properties. See the Appendix for a summary of the instruments.

Patient Activation Measure

The Patient Activation Measure (PAM-13) was developed by Hibbard et al. (2004). The 13-item instrument is an interval-level assessment containing items that measure self-assessed knowledge about chronic conditions, beliefs about illness and medical care, and self-efficacy for self-management. The PAM-13 is scored on a range from 0–100 that stratifies a client to one of four interval-levels (Level 1: believes active role is important, Level 2: confidence and knowledge to take action, Level 3: taking action, and Level 4: staying the course under stress), with a higher score indicating higher activation levels.

Patient Engagement Measures

The Patient Health Engagement Scale (PHE-S) was developed by Graffigna, Barelo, Bonanomi, and Lozza (2015). The scale consists of five ordinal items that features four positions along a continuum of engagement (i.e., blackout, arousal, adhesion, eudaimonic project) and assesses clients' degree of emotional elaboration and adjustment reached concerning their own health condition when engaging in health management. The blackout phase occurs when a client's health care experience feels overwhelmed, represented by emotional fragility, passiveness, and withdrawnness such that they rely on others (i.e., caregivers, health care professionals, etc.) for significant decision and action about their health care concerns. The arousal phase occurs when a client acquires firsthand knowledge about their health condition and begin coping with the condition such that they appear hypervigilant, anxious, overreactive, and focused on the sick body. A client in adhesion has accepted their condition but is unable to navigate unexpected events related to their illness or the health care context such that the client can easily relapse into a state of arousal or blackout. Lastly, a client in the eudaimonic project has fully accepted their health condition and appears to play an active role in their health and the health of others such that the focus is on the client as a person and their continued routines of daily activities.

The Pittsburgh Rehabilitation Participation Scale (PRPS) is a valid and reliable criterion-referenced scale that measures the degree of active participation in rehabilitation therapy sessions (Lenze et al., 2004b). The scale considers the proportion of prescribed activities in which clients actively participated, given levels of interest, effort, direction following, and completion scored on a 6-point Likert scale (1 = *no participation, refusal to*; 6 = *excellent participation*). Standardized training is required prior to administering the instrument.

The Hopkins Rehabilitation Engagement Rating Scale (HRERS) is a 6-point Likert scale consisting of five items in the single domain of engagement that measures therapy attendance, attitude toward rehabilitation, and participating behavior (Kortte et al., 2007).

The Rehabilitation Therapy Engagement Scale (RTES) is a 4-point Likert scale instrument containing 15 items assessing attitude, perceptions, and expectations that influence engagement and performance (Lequerica et al., 2006). The purpose of the instrument is to document a client's level of engagement in rehabilitation to identify problematic areas for targeted interventions.

When to Use Patient Engagement or Patient Activation Assessments Versus Functional Interventions?

The undeniably fast pace and high productivity demands for occupational therapists in acute care hospital settings make it difficult to administer additional outcome measures. Taken together, the economic costs for rehospitalizations and policies from the ACA penalize hospitals for targeted clients readmitted within 30 days; therefore, it is imperative for occupational therapists to identify clients that are at high risk for rehospitalizations. Occupational therapists have the skills and lens to identify clients that are most susceptible to having a poor understanding of their own health and poor self-management behaviors. For guidance and suggestions of when to administer PAE assessments, see Figures 1 and 2.

Figure 1
Prioritizing Patient Engagement Assessments versus Functional Interventions

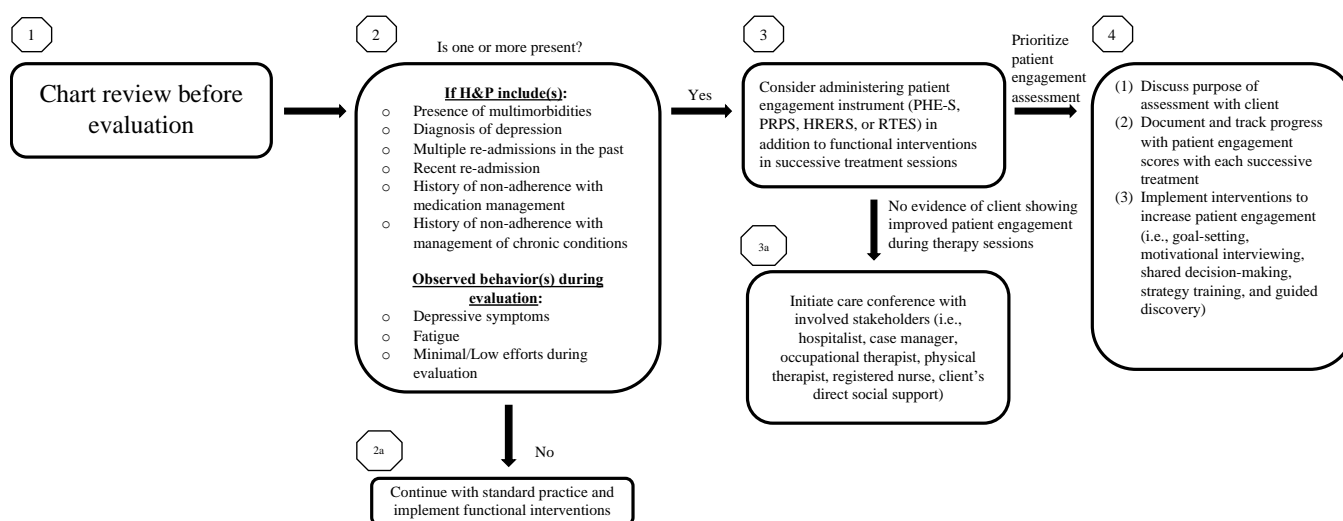
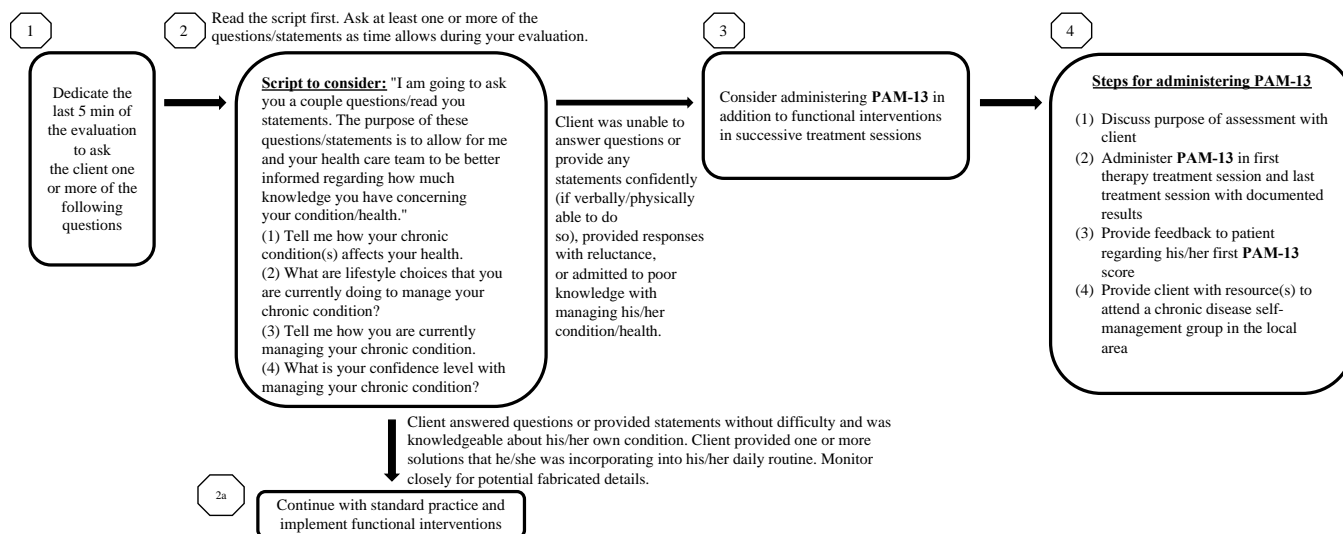


Figure 2
Prioritizing Patient Activation Measures versus Functional Interventions



Activation Levels and Health Behaviors

Patient activation levels are considered one of the most reliable variables to predict clients' willingness and ability with self-management skills (Graffigna, Barello, Bonanomi, Lozza, & Hibbard, 2015; Greene et al., 2015; Hibbard, 2003). Self-management is a dynamic, interactive, and daily process in which persons engage to manage a chronic illness and is conceptualized as the ability of the individual, in conjunction with family, community, and health care professionals, to manage symptoms, treatments, and lifestyle changes of health conditions (Lorig & Holman, 2003). The relationship between patient activation and self-management has been heavily researched to demonstrate associations specifically in engagement of preventive behaviors, delayed medical care, and self-care management across different chronic conditions.

Preventive Behaviors

Several studies demonstrated empirical evidence that more activated clients engage in more preventive behaviors, such as having regular health check-ups, screenings, and immunizations (Harvey et al., 2012; Hendriks & Rademakers, 2014; Shively et al., 2013; Smith et al., 2013). A cross-sectional study of clients with diabetes in an urban public hospital followed over 6 months found that clients with higher levels of activation were more likely to perform weekly foot checks, receive eye examinations, and exercise regularly (Rask et al., 2009). Among persons with severe mental illnesses, higher activation levels were predictive of having better self-management and recovery skills and were less likely to have a substance abuse problem (Salyers et al., 2009). Poorly activated clients have decreased awareness and are not equipped with the readiness to understand the importance of engaging in preventive behaviors. Therefore, occupational therapists should be at the forefront of beginning the conversation with poorly activated clients through informal interviews or formal assessments to understand the client's readiness to create a client-centered schedule or routine for regular medical appointments to avoid further complications from their chronic or new acute conditions.

Delayed Medical Care

When compared with more activated clients, less activated clients are twice as likely to have delayed medical care and 3 times as likely to have unmet medical care (Hibbard & Cunningham, 2008). In a study comparing patient activation levels among U.S. born and non U.S. born clients, non U.S. born clients had a greater percentage of being the least activated with reported themes of delayed medical care such that it was better not to know about an illness (Lubetkin et al., 2014). Although limited studies have assessed the relationship between patient activation and delayed medical care, low health literacy was more common among less activated clients and was predictive of delayed medical care (Levy & Janke, 2016; Smith et al., 2013). Common reasons for delayed medical care among clients with low health literacy included the inability to (a) afford the cost, (b) receive appropriate transportation, (c) tolerate the long waiting times at the doctor's office, (d) cope with the new findings about their health, and (e) find a provider or have access to a usual source of care (Levy & Janke, 2016). It should be cautioned when interpreting these findings that health literacy and patient activation are two different constructs and have been found to have independent influences on health outcomes. Despite these results, the relationship between a client's activation levels and delayed medical care remains promising and deserves further investigating. Although often outside the scope of acute care practice for occupational therapists, making medical appointments is considered an instrumental activity of daily living for people. It should become standard practice for occupational therapists in the acute care hospital setting to introduce resources and instruct clients to ensure they make their appropriate medical

appointments. Poorly activated clients may not understand how to obtain the necessary resources to overcome the barriers often reported that delay their access to medical care. Communicating with the client's case manager or hospitalist about the client's concerns about affordability, transportation, or finding a provider is a great first step toward relieving the client's stress and anxiety. Other solutions that occupational therapists should provide are evidence-based handouts containing information about the client's new health status that can assist with coping. In addition, occupational therapists should refer clients to participate in support groups specializing in chronic disease self-management skills to increase peer support, improve psychosocial well-being, develop positive lifestyle changes, and increase use of community resources.

Self-Care Management

Clients that scored higher on PAM-13 had better chronic disease self-management (Hibbard et al., 2007; Hibbard et al., 2009). Highly activated clients with heart failure in a hospital setting reported better self-care management behaviors and strategies, such as reducing dietary salt, reducing fluid intake, taking an extra diuretic, or calling a doctor or nurse for guidance in response to worsening symptoms when compared to the same cohort that was poorly activated (Creber et al., 2017). In the same study, higher activation was also associated with better self-care behaviors, including adherence to medications, diet, and exercise, as well as self-management of symptoms (Creber et al., 2017). Changes in activation levels have also been shown to influence changes in self-management behaviors. Hibbard et al. (2007) found that positive changes in activation levels among clients with at least one chronic condition was related to positive changes in a variety of self-management behaviors. Specifically, clients that had the largest growth in activation levels demonstrated improved behavior patterns that included: engaging in regular exercise, managing stress, paying attention to the amount of fat in their diet, keeping a blood pressure diary, keeping a glucose diary, and taking diabetes medications as recommended (Hibbard et al., 2007). If working with clients with a lower PAM-13 score, it should become obligatory and part of standard practice for occupational therapists to make referrals for clients to participate in a chronic disease self-management program, as such programs have been effective in improving client outcomes among several populations with different chronic conditions. Occupational therapists are also experts in assisting clients manage their medication routine, improving medication adherence, creating client-centered home exercise programs, and learning general dietary recommendations to promote optimum health outcomes.

Occupational Therapy and Patient Activation

Interventions that occupational therapists can address in the acute care hospital setting can be directly driven from the client's score on the PAM-13. Items that the client scored *disagree* or *disagree strongly* can be addressed through interventions incorporating meta-cognitive training, problem-solving training, verbal self-instruction, role-playing, shared decision-making, motivational interviewing, strategy training, and guided discovery. See below for an example.

1. I know what each of my prescribed medications do. *Disagree strongly*
 - a. Print out the client's list of medication.
 - b. Create a new document listing all of the client's medication.
 - c. Explain in layman's terms the purpose of each medication. Have the client create their own working definition for the purpose of the medication and how it affects their health if they stop taking the medication or take the medication incorrectly.

- d. Have the client develop an organized method and routine for taking their medication on time.
- e. Use a teach-back method for all of the steps above to ensure that the client feels confident with their medication adherence routine.

Clinical Variables Predictive of Engagement in Rehabilitation

Patient engagement has gained popularity as a term that has been loosely used in the health care setting. Two popular investigators have proposed different definitions and frameworks to conceptualize patient engagement. Hibbard (2003) referred to patient engagement as a broader concept combining patient activation with interventions designed to increase activation and promote positive client behavior. Bright et al. (2015) proposed patient engagement and its relevance to rehabilitation as a co-constructed process between a client and practitioner involving a gradual connection between both parties. Despite the inconsistencies, a recent review aimed to conceptualize patient engagement summarized the construct to include the following thematic content: connection between the client and practitioner or service, the development of a mutually trusting relationship or connection between two parties, the clinician having a pivotal role in the process of engaging the client, clients having the ability to communicate to ensure they were listened to and understood, clients having active participation in therapy tasks, active commitment and high level of interest invested in therapy from the client, and clients contributing to the decision-making process of care (Bright et al., 2015).

Multiple investigators have argued that the benefits of rehabilitation are limited if a client is not completely engaged in the therapeutic process. In particular, high levels of patient engagement were found to be associated with better functional improvement and less depressive symptoms among clients with spinal cord injury, ischemic or hemorrhagic stroke, amputation, and hip or knee replacement in an acute care hospital at discharge with sustained improvements of functioning 3 months post discharge (Kortte et al., 2007). Table 1 summarizes an overview of clinical variables and external predictors of patient engagement levels.

Table 1

Clinical Variables Related to Poor Rehabilitation Engagement and Participation

Clinical Variable	Supporting Evidence
Age	¹ Significantly older clients had lower engagement and participation levels after rehabilitation training and is considered a negative prognostic factor for poor participation (particularly for clients with a stroke)
Cognition	² Cognitive impairments (decreased attention, memory, and executive functions) have been identified as negative predictors of participation and engagement during rehabilitation
Co-morbidities	³ Increased numbers of co-morbidities had worse functional gain and decreased participation and engagement
Depression	² Depressive symptoms were significantly correlated with poor participation and engagement levels in rehabilitation (particularly during the first weeks of rehabilitation)
Fatigue	⁴ Higher fatigue levels showed poorer participation and engagement in rehabilitation with a reported frequency of 38%–77% among clients with a stroke
*FIM score	⁵ Among clients with a variety of impairment diagnoses, improved scores on the 13-item FIM motor assessment during inpatient rehabilitation stay was significantly better for highly engaged clients compared to poorly engaged clients
Gender	⁶ In clients with stroke, female gender was identified as a negative prognostic factor for patient engagement and participation

Intensity of treatment in rehab	⁷ Clients following a hip fracture that engaged in higher intensity of treatment in rehab (measured by Actigraphy) during therapy were more likely to have higher engagement levels along with better functional outcomes at 3 and 6 months while achieving 78% and 91% recovery of pre-fracture function compared to those who were less active achieving 64% and 73% recovery
Self-efficacy	⁸ Highly engaged clients reported better self-efficacy, such that they understood the necessity for rehabilitation, acknowledged the role of medical professionals, and endorsed the belief that effort was essential to make improvements and achieve independence. Poorly engaged clients endorsed the need to wait for recovery, did not understand the purpose of rehabilitation treatments, expected things to be done for them, and had low initiative to participate

Note. *FIM = Functional Independence Measure¹(Paolucci et al., 2003); ²(Skidmore et al., 2010); ³(Morghen et al., 2017); ⁴(Yang & Kong, 2013); ⁵(Lenze et al., 2004a); ⁶(Gargano & Reeves, 2007); ⁷(Talkowski et al., 2009); ⁸(Maclean et al., 2000).

Occupational Therapy and Patient Engagement

Are occupational therapists actively practicing the core value of client-centeredness incorporated in PAE approaches? Past researchers found that occupational therapists lacked the skills and understanding of using a client-centered approach (Corring & Cook, 1999; Sumsion & Smyth, 2000; Wilkins et al., 2001). Engaging and encouraging clients to become an active participant in their own rehabilitation process is central to the occupational therapy profession, and client-centered goals should be incorporated in every therapist and client interaction. Despite the importance of client-centeredness reflected in the professional standards established by American Occupational Therapy Association, there are numerous barriers to appropriate implementation of the approach. In a study comparing client and occupational therapists' perceptions of the process of client-centered care, barriers to implementing client-centered practice included: (a) clients with decreased cognition, (b) clients that had no desire to contribute to setting personal goals and expected therapists to set goals for them, (c) facility productivity demands, (d) clients that were unable to verbalize their concerns, (e) practice settings in which the client's personal goals were not appropriate for the health care team's agenda, and (f) clients that were indifferent and unmotivated to be independent (Maitra & Erway, 2006). However difficult it may be to motivate a client to understand the importance of being an active participant in their own care, a client's level of engagement can be influenced by a therapist's level of engagement. A recent study found that poorly engaged clients who struggled or did not understand and hated therapy were influenced to become more engaged by therapists who showed a passion for the job, personalized treatments to meet individual clients' needs, and had positive non-verbal communication (Bright et al., 2017). In contrast, clients reported that their motivation to participate in therapy was affected by disengaged therapists described as focusing on service requirements, seeming disconnected or disengaged, and doing only the legal obligations of the job title (Bright et al., 2017). In the same study, disengaged therapists often positioned the responsibility on the poor engagement levels of the client. The occupational therapists felt powerless to change the client's perspectives, discharged clients until the client was ready to engage, and lacked the confidence or knowledge to make a difference (Bright et al., 2017). As a result, an occupational therapist's engagement level could beget a client's engagement.

Practical Strategies for Poorly Engaged Clients in the Acute Care Hospital Setting

Despite the multifaceted challenges presented by poorly engaged clients, occupational therapists' clinical energy should be expended more on poorly engaged clients, as they often have worse functional outcomes and difficulty with discharge planning. One practical strategy to help increase the client's engagement is a care conference. A care conference calls for all involved stakeholders (i.e., hospitalist,

case manager, occupational therapist, physical therapist, registered nurse, and the client's direct social support, if available) having a direct conversation with the client to discuss a plan of care that aligns with the client's goals. During the care conference, the occupational therapist should objectively address the client's performance in therapy sessions, level of engagement, behaviors during treatment sessions, and progress toward functional goals. In addition, the occupational therapist should reiterate the purpose of occupational therapy in the acute care hospital setting, the functional goals that need to be met for safe discharge, and the level of engagement required for the client to achieve their functional goals. Lastly, a significant portion of the care conference should allow for the client to verbalize their concerns, barriers to participating in therapy, and any scheduling disruptions in the hospital that impact engagement in therapy sessions. To conclude the care conference, an informal contract agreed on by the client and occupational therapist should be developed and posted inside the client's room that verbalizes all barriers and concerns limiting the client's progress with engagement in occupational therapy treatment sessions.

Conclusion

Patient activation has important implications for rehabilitation outcomes in the acute care hospital setting. Although limited evidence is available specific to the field of occupational therapy, occupational therapists remain important stakeholders in facilitating improved rehabilitation outcomes among clients with a variety of disabilities and chronic diseases. The onset of a new disability comes with the responsibility of being able to understand, develop the skills, and have the confidence to manage the chronic conditions that will ensue in the client's future. The management and understanding of the new chronic conditions become a new occupation for the client as they first experience their new disability. Occupational therapists in the acute care hospital setting have the first opportunity to begin the process of increasing a client's activation level to bring new insights into developing positive self-management behaviors, engaging in preventive care, and adhering to treatment plans.

The values and foundation of occupational therapists are embedded in patient engagement. Occupational therapists are skilled in actively giving clients a voice and active role in the therapeutic process along with using shared decision-making strategies to develop goals. Ensuring that clients are engaged does not come without its barriers. While occupational therapists encounter productivity challenges and feelings of powerlessness when faced with poorly engaged clients, the responsibility should not be positioned solely on the client. As patient engagement is co-constructed by continuous interactions between therapist and client, occupational therapists should seek guidance from the core values of our profession to ensure that treatments and goals continue to be meaningful and personal.

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Appendix

Summary of Patient Activation and Engagement Measures

Patient Activation and Engagement Instruments					
Instrument	Purpose	Construct	Scoring	Domains/Items	Author
PAM-13	Self-report measure assessing a patient's knowledge, skill, and confidence in managing their health or chronic condition.	Patient Activation	Scored from 0-100. Level 1 (0.0-47.0) suggests that a person may not yet understand that the patient's role is important. Level 2 (47.1-55.1) indicates that a person lacks the confidence and knowledge to take action. Level 3 (55.2-72.4) indicates that a person is beginning to engage in recommended health behaviors. Level 4 (72.5-100.0) indicates that a person is proactive about health and engages in many recommended health behaviors.	(1) Believes active role is important, (2) Confidence and knowledge to take action, (3) Taking action, & (4) Staying the course under stress.	Hibbard et al., 2004
PHE-S	Measures the degree of emotional elaboration and psychological adjustment reached by the patient concerning his/her own health condition when engaging in health management.	Patient Engagement	Self-reported 5 ordinal items measured on a 7-point scale.	(1) Blackout phase, (2) Arousal phase, (3) Adhesion phase, and (4) Eudaimonic project phase.	Graffigna et al., 2015
PRPS	Measures the degree of active participation in an observed rehabilitation therapy session.	Patient Engagement	Six-point Likert-type measure scored by the treating therapist to assess the patient's participation (effort and motivation as perceived by the therapist) in a therapy session. (1) None: patient refused entire session or did not participate in any exercises in session, (2) Poor, (3) Fair, (4) Good, (5) Very Good, and (6) Excellent: patient participated in all exercises with maximal effort, finished all exercises, and actively took interest in exercises.	Participation in rehabilitation therapy session.	Lenze et al., 2004b