Patient Activation: What It Is and How Registered Dietitian Nutritionists Can Make It Happen

The idea of engaging patients in their own health care is one deeply rooted in the concepts of wellness and prevention. The evolving model by which health care is managed in America places more financial responsibility on both patient and provider alike for positive outcomes, necessitating an increase in participation by all involved. Numerous studies affirm what practitioners have long known to be true, that the more engaged a patient is in their own health care, the better their health is likely to be.1–3 As would be expected, tools to assist in this process have been developed, from the Patient Activation Measure (PAM), to other models such as the Patient Health Questionnaire-9 (PHQ-9) and Short Form-12 Health Survey (SF-12), to in-house creations homespun by practitioners across the country.

The need for registered dietitian nutritionists (RDNs) to be both providers and educators will increase as hospital re-admissions are more heavily scrutinized and wellness becomes more valued. This concept of patient engagement is referred to as activation, which is defined as the capacity and willingness to take on the role of managing one’s own health and health care.4 Reading up on this issue can accentuate an RDN’s understanding of patient activation, inform them about tools to measure and improve these levels, and thereby help them achieve better outcomes. All of this translates into increasing the value of health care organizations bringing RDNs to the proverbial table and continued evolution for the field at large.

The growing importance of activation

Just as with any learning process, patient activation requires the empirical measurement of awareness, knowledge, and learning at all stages of treatment. One must determine where a patient stands in terms of awareness before any increase or improvement can be measured. Diagnostic tools such as PAM, PHQ-9, and SF-12 are becoming more prevalent in the dynamic landscape of health care, where wellness and prevention are looked at as cures in advance. RDNs may consider incorporating tools such these into their practice to both measure and improve their patients’ participation in and awareness of their overall health, in addition to the specific condition being treated.

The widely adopted Chronic Care Model—which serves as an organizing framework for the improvement of chronic illnesses—calls for health care system redesign that enables proactive teams of clinicians to interact with “informed, activated patients,” or patients who have the motivation, knowledge, skills, and confidence to make effective decisions to manage their health. Developed in 1998 by the nonprofit Improving Chronic Illness Care,5 a prominent feature of the Chronic Care Model is the assumption that improvement in care requires an approach that incorporates patient-, provider-, and system-level interventions. This model was born with the idea that chronic problems are multifactorial in nature and that successful interventions require dynamic steps that address the psychosocial and lifestyle issues of patients, as well as the physical ailments. The significance of patient activation has been recognized in current health care reform efforts.6

RDNs in some fields have been using these principles for a number of years, whether in conjunction with PAM or with in-house surveys. As Meghann Featherstun, MS, RD, LD, a clinical dietitian and wellness coach at University Hospitals Accountable Care Organization at University Hospitals of Cleveland, pointed out, the idea of activating patients hearkens back to lessons learned in her undergraduate classes involving the transtheoretical model for change developed by James Prochaska, PhD, currently director of Cancer Prevention Research Center at the University of Rhode Island. The transtheoretical model of behavior change, Featherstun remarked, integrates stages, processes, and levels of change and has been applied to health issues ranging from diet and exercise to mental health.

“You have to meet the patient where they are,” Featherstun said, pointing out that some patients might not even be aware of the relationship between their behavior and health. This is particularly true in terms of nutrition, which the patient might not realize can impact everything from mental to physical health. Various socioeconomic factors, including education and family history, can greatly impact a patient’s awareness of health care, she said. Without taking the patient’s level of understanding into consideration, Featherstun noted, it is difficult to succeed as an RDN.

Likewise, Tracey Smith, MPH, RDN, a supervisor in Moda Health Plan’s division handling patients with chronic conditions, said diagnostic tests are integral to the role of health coaching. Her division, which often works with patients battling three to four chronic conditions simultaneously, has been...
Ways to Increase Patient Activation:

- First, increase your own activation. Introduce the topic for discussion within the Dietary Practice Groups in which you participate. Fellow RDNs are a great resource for new tools, be they available through private industry or generated in-house.
- Read up on the growing body of literature and evidence-based studies on patient activation. Contact the Academy of Nutrition and Dietetics Professional Development staff to see what resources are available to members.
- Discuss the idea of formalized patient activation with your employer, or within your own private practice. Determine how best to incorporate it into the practice.

Remember, raising awareness and understanding in patients is key to increasing activation. The same holds true for one’s own self. By increasing one’s own awareness of the factors at play, one will be better able to understand and address the needs of others.

Using PAM since 2008, as a pretest, and at intermittent points throughout treatment.

“I think that it’s growing by leaps and bounds,” Smith said in reference to the idea of patient activation, adding that, in her opinion, such tools can be used in working with patients across the broad spectrum of health care.

Patients are becoming more influential in the discussion of health care costs and quality.1 This trend is only expected to continue as consumer-directed health plans are predicated on the ability of consumers to make informed choices. The concept assumes at the most basic of levels that the patient as a consumer will be more prudent in their health care decisions if given financial incentives in conjunction with comparative cost and quality information. Moreover, the Chronic Illness Care Model focuses on patient-oriented care, with an emphasis on the patient and if possible family members incorporated into the care team.1 Activated patients are clearly critical if this is to be accomplished.

Research involving multiple tools— including PAM, SF-12, and PHQ-9— shows a strong link between better health outcomes and a patient’s engagement and activity level.1,7 The same relationship exists between patient engagement and measurable cost savings.5,7 Meanwhile, research indicates that average patients have considerable difficulty navigating the health care system, which drastically reduces the efficacy of their treatment plans by impeding timely visits and reduction of access.1,7,8

Each tool offers a slightly different focus, specifically designed to address unique needs. The SF-12 was developed for the Medical Outcomes Study, a multi-year study of patients with chronic conditions. The product is a short-form survey, which its designers felt would work well with clinicians restricted by survey length, where the burden on the respondent is lessened while still seeking a broad comparison involving multiple health dimensions.5 The PHQ-9 meanwhile was initially designed to gauge depression treatment outcomes.7 Like the SF-12, the PHQ-9 offers a significantly shorter series of questions than PAM, and researchers using it cite its brevity as one of its attributes in treating depression.5 Researching the differences offered by each tool will allow the practitioner to capitalize on the overall concept of activation, which seeks to heighten patient involvement.

PAM: AN EXAMPLE FOR MEASURING ACTIVATION

Just as it sounds, the concept of activation revolves around an active, as opposed to passive, approach to wellness. Assessing one’s level of activation can be accomplished by tools such as PAM, a survey-based diagnostic approach designed to measure this quality, developed by researchers at the University of Oregon, currently licensed to Oregon-based Insignia Health. The test is a 13-item measure involving a unidimensional, interval level, Guttman-like scale on which patients score between 0 and 100 across four activation levels. Guttman scales, as opposed to Likert or Thurstone scales, are formed in structured interviews and questionnaires in which subsets of items have responses offering varying degrees of agreement, which allows the answers to be ranked so as to establish a response pattern: in the case of PAM, one involving multiple stages. Those four stages are: 1) the belief that the patient role is important, 2) possessing confidence and knowledge necessary to take action, 3) taking action to maintain and improve health, 4) staying the course even under stress.1

Research conducted by the University of Oregon team that ultimately developed PAM indicates that at Stage 1, patients most likely do not fully understand that they must play an active role in their health, and may see themselves as passive recipients of programming or medicine.7 As an example, only 12% of patients aged 45 years or older, when surveyed nationally, answered in the affirmative that, “When all is said and done, I am the person who is responsible for managing my health condition.”7 Stage 2 finds patients lacking basic facts and understanding of the connection between health and treatment regimens. Examples from a national survey of adults aged older than 45 years demonstrated that only 29% answered in the affirmative, “I know the different medical treatment options available for my health condition,” and “I know what each of my prescribed medications does.”2 At Stage 3, patients may have key facts and begin to take direct action, but may lack the requisite skill to achieve the new behaviors. Examples from the survey reported that 37% of adults older than age 45 years answered in the affirmative, “I know how to prevent further problems with my health condition,” and “I have been able to maintain the lifestyle changes for my health that I have made.”2 The fourth and final stage is one in which patients have adopted new behaviors but may have difficulty maintaining them when confronted with stress. Examples from the national survey indicate that only 22% answered in the affirmative, “I am confident I can figure out solutions when new situations or problems arise with my health condition,” and “I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.”2

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TRANSLATING ACTIVATION STAGES INTO APPLICATION BY RDNs

These stages of activation provide insight into possible strategies for supporting activation among patients at different points along the continuum. Determining a patient’s activation level is essential to knowing whether they are truly capable of following prescribed meal plans or routines once home. In an article describing the impetus to develop PAM, its lead researchers explain that the changing landscape of health care is necessitating patients taking a more active role in the process, and the level of their activity is directly related to their understanding of the situation. As an example, Featherston said her accountable care organization (ACO) has facilitated access to the Personal Health Record for each of its 200,000 covered lives. This, she said, is one example of using information to help inspire questions and discussions that can ultimately raise a patient’s score.

Patients who are able to self-manage conditions and symptoms, engage in activities that maintain function, participate in diagnostic choices, collaborate with providers, select provider organizations based on quality, and successfully navigate the health care system are more likely to have better health outcomes.1 Given this, the logical series of questions that follows is thus one involving how to go about determining these levels within patients, and how to use that information for the purpose of improvement. Using empirical measures to gauge a patient’s activation allows an RDN to effectively track their progress and ultimately improve that score while administering care. Evidence strongly supports the idea that this is a worthwhile endeavor.

Since 2004, a number of cross-sectional studies have reported higher PAM scores to be correlated with healthy behaviors, including physical activity and proper diet, appropriate use of the health care system, and more educated decision-making processes in the selection of health care professionals and facilities.6 This includes better skill-sets in managing chronic illness as demonstrated by hemoglobin A1c (HbA1c) control and fewer hospitalizations.8 A cross-sectional study based on 2010 Electronic Health Record data of 25,047 adult patients demonstrated a direct link between higher activation scores and lower probability of emergency department visits, obesity, or smoking.9 The study measured 13 patient outcomes across four areas: prevention, unhealthy behaviors, clinical indicators, and costly utilization, with PAM serving as the key independent measure. The study sample was 65% female, with an average age of 50 years. Patients had on average one chronic condition. The rate of smoking for the study was comparable to the state average at 17%, whereas obesity rates were substantially higher, 40% vs 25%.

The study by Greene and Hibbard links patient activation to at least 12 patient outcomes, demonstrating that for every additional 10 points of activation, the probability of an Emergency Department visit, obesity, or smoking was one percentage point lower.10 In addition to a relationship between activation and outcomes, the study noted that the per capita median income of the patients’ zip codes was likewise related to their demographics, health, and utilization incomes. Patients living in higher-income areas manifested activation scores nearly two points higher than their lower-income counterparts. Likewise, patients in higher-income areas were found to be less likely to smoke, be obese, or use the emergency department. Overall, their clinical indicators were more likely to be in the normal range, and they reported more cancer screenings, suggesting linkage between higher activation, income, health, and perhaps overall quality of lifestyle, as patients with higher activation scores reported higher usage of wellness care. The investigators noted, “The findings highlight the potential role that patient activation can play in improving quality and health outcomes.”

The link between activation score and testing results was also observed in diabetics, in which PAM scores from a 2004 survey of 1,180 random adult diabetics were studied.11 PAM scores were found to be predictive for HbA1c testing (P<0.008), low-density lipoprotein cholesterol testing (P<0.005), HbA1c control (P<0.01), and all-cause discharges (P<0.03), but not for lipid-lowering drug use, low-density lipoprotein cholesterol control, or acute myocardial infarction discharges. These results suggest that PAM scores can be used to identify patients at risk for poorer health outcomes.9 The lack of positive association between PAM and the acute myocardial infarction discharges was attributed to the relatively small number of such discharges within the study population.9

The study concludes that activation, as measured in the PAM, can be predictive. Patients exhibiting higher scores are more likely to follow recommendations and medical advice. This, the researchers believe, correlates with reduced use of future health care services.

CONCEPTUALLY VALID

The idea that patients’ outcomes can be improved through engagement and education is not new to clinicians, particularly those dealing with chronic conditions. Studies indicate that interventions designed specifically to treat chronic disease patients can significantly reduce both hospitalizations and days of hospitalization.10

Smith explained that, in her experience, individuals suffering multiple chronic conditions can become overwhelmed with information overload and the complications of their situation. A vicious cycle ensues whereby one’s low level of engagement may in fact cause a disorder, or complicates one enough to lead to another, thereby driving one’s activation lower yet, and worsening the situation. Depression may be a factor, and this can make it difficult to treat the patient, whether getting them to follow a prescribed plan or even show up for appointments, she said. Getting a quantitative score to measure the patient’s attitudes at the onset of treatment can help the RDN determine the best method of approach. Retesting throughout the treatment can measure success and further activate the client, she added.

Featherston explained that the ACO for which she works handles more than 200,000 covered lives and is integrated into the University Hospitals of Cleveland system. Professionals within that size of an organization use a number of programs such as PAM, many tailoring the tool to fit their specific needs, be they for nursing,
therapy, or nutrition. The importance of implementing those principles cannot be overstated, she said. “That’s what we do, day in and day out, in an ACO,” she observed.

Both said that in their experience, the link between patient activation and health outcomes is unmistakable. Featherstun explained her own role within an organization-wide healthy weight-loss program for employees. Increasing the level of ownership participants take in their own weight loss is crucial, she said. Meanwhile, the struggle to activate patients in such a manner is consistent across age groups, with teenage patients often being as disengaged as elderly people, she said. Patients whose condition has led to an acute event tend to become more interested, however, because of the scare.

“The biggest thing I see is motivation,” Featherstun said, noting that without it, changing one’s behavior is extremely difficult. The second obstacle is often a lack of self-confidence in one’s own ability to manage his or her health. Both can be remedied with patient education, and both require some understanding of where the patient stands in terms of awareness.

Both of these issues can be addressed via the use of tools such as PAM, she and Smith observed. In many cases, simply participating in the survey process can help raise awareness of health in patients who might otherwise never consider it.

References