

Chapter 9

“A” Is for Activating



9.1 Patient Activation: The Concept and the Practices

There are a number of concepts used in medical literature to reflect the understanding that despite advances in medical treatments, the largest factor in how well patients with chronic diseases do in the long run is a product of how well they take care of their own health. Whether or not they take their medicine, get exercise, avoid tobacco or too much alcohol, eat a healthy diet, and do other actions to control their particular chronic illness will make a major difference in how well they are able to function and in how long they live. Where the standard of care was once focused largely on proper prescribing and other actions taken by health professionals, now the standard of care is becoming focused on ways of influencing patients to do their part in their own care.

In the case of chronic illness care, the patient is the most important member of the team, whether health professionals or patients like it or not. Concepts such as stages of change in health behaviors [1], health locus of control [2], self-efficacy in self-management [3], self-determination theory [4], and patient engagement [5, 6] reflect the array of efforts at understanding what makes patients more likely to take the actions that only they can take to improve or maintain their health. Each of these concepts is now supported by a metric to locate a patient's functioning with regard to an ideal. Some of these concepts have spawned broad adoption efforts involving training of professionals to use the methods shown to move patients along the metric of the concept.

The concept of “patient activation” is one in this line of research, one that has rapidly growing acceptance currently. The concept measures an amalgam of the will, the knowledge, the skills, and the confidence that the patient has, to predict the likelihood that they will take the actions necessary to manage their illnesses and to stay healthy. It has had broad acceptance in part because of the elegance of an instrument for measuring patient activation that embodies a rigorous definition to the concept. The Patient Activation Measure (PAM) [7] is good at distinguishing

which patients are likely, and which are not likely, to be active in self-care for their chronic illnesses. Because of its success as a prediction of health behavior, it can be used as an intermediate outcome to measure interventions that would take too long to show the changes in patients’ health status that good self-care eventually brings [8]. The ability of the PAM to sort patients hierarchically into groups that are more and less likely to do successful self-care means it can be used to target specific interventions to patients based on their answers to the questions of the measure.

The Patient Activation Measure was constructed through a multistep process involving many experts and patients that isolated a consensus list of the core elements of “activation” in healthcare [7]. The measure is based on self-report of the patient about their beliefs and abilities. The original form of the PAM had 22 items, but a reliable short form with 13 items was developed shortly after the introduction of the first form [9]. The 13-question short form and a subsequent 10-question version are both currently in wide use. Subsequent testing has shown that people whose responses are higher on the PAM tend to behave in more activated ways in relation to their health. The beliefs and self-descriptions measured by PAM do predict people’s health behaviors well. It sorts patients into groups that can be studied further.

The PAM is built on a developmental model of activation, meaning that it assumes that patients go through the PAM’s four levels of activation in sequence. A patient with low activation is likely to first need to believe that they have an important role to play in maintaining their health and then to gain elementary knowledge about their condition and their treatments. Those who achieve that step will then need to develop skills and confidence so that they practice self-care for their specific illness burden. Finally, in their development toward higher levels of activation, they need to learn to maintain their health gains in the face of stress.

One shortcoming of the PAM is that its concept of activation tends to be patient focused rather than patient-in-context focused. It measures the patient’s ability to maintain gains in relation to context factors (stress) only for the highest stage of activation. The impact of stress on patients’ confidence in their importance as part of their healthcare team, or in their ability to take the actions that are needed for self-management, for example, is not measured.

The role of context, however, is very important in understanding which patients are identified as being at different levels of activation. While there have not been any nationally representative samples done, multiple smaller studies have found that demographics are powerful correlates of activation [10–12]. In a study by Smith and his colleagues [12] of 3400 patients, higher patient activation was shown to be associated with higher income ($p < 0.001$), higher levels of education ($p < 0.01$), better self-rated health ($p < 0.001$), and having fewer chronic conditions ($p < 0.05$). Wealthier, better educated patients who have fewer illnesses and feel that they are healthy are the people who show up as most activated on the PAM. The converse wasn’t stressed, but the data said that patients with lower incomes and lower education levels, who experience themselves to be in poorer health, are the patients that the PAM shows to have lower levels of activation. The more a patient might be

classified as “complex” in other literature, or as fitting the “multiply-disadvantaged” term we have used in previous chapters, the lower their initial activation score is likely to be. Demographics are not destiny, however, in that patients with low activation scores can make the most gains when interventions to improve activation are offered [13].

Patients with lower activation scores tend to have different ideas of what constitutes good self-care than patients with higher scores based on their having different understandings of what constitutes an ideal relationship between a patient and their doctor [14]. This study involved in-depth interviews with patients whose scores represented every level of activation. At lower levels of activation, patients identified compliance with the directions of the doctor as constituting better self-management of their condition. They believed that patients who do what they are told to do by their doctor are doing their part of the physician-patient relationship. At higher levels of activation, patients identified partnership with the doctor as the best physician-patient relationship for successful self-management.

Given the finding about patients’ different conceptions of the doctor-patient relationship, it makes sense that less activated patients have been found to be less likely to perceive shared decision-making with their doctor as a value. As patients’ level of activation rises, they report interest in sharing decision-making with their doctors on more types of medical decisions. The most activated patients want to participate in shared decisions relating to lifestyle, preventive screening, choosing treatments, choosing between medications, and deciding the necessity of a diagnostic test [12]. Patients with low levels of activation, complex patients, cannot be assumed to want to participate in shared decision-making despite the literature that promotes shared decision-making as the fix for building partnership for complex patients [15].

Another difference between patients with low and high activation scores was identified by Aung and her colleagues [16] when they added a measure of patients’ experience of the quality of care that they receive to the assessment of their level of activation. All of the patients in the study had type 2 diabetes. The outcome measure was the level of glycemic control patients maintained. For patients with high levels of activation, the quality of care had little effect on their glycemic control. They tended to have good control, whether or not they thought they were getting the best care. It was for patients with low activation that the quality of care made a significant difference in how well they controlled their blood sugar. Patients tended to interpret their perceptions of the quality of care they got as reflecting their health professionals’ judgment of the care they deserved. Whether or not they are seen by their health professionals as deserving the best care was important to the patients we have called “multiply-disadvantaged” and made an important difference in their levels of adherence.

While some approaches emphasize patients’ lack of knowledge about their chronic condition as a central explanation for poor self-management [17], in the study by Dixon et al. [14], lack of knowledge was identified by only a small number of low activation patients as a barrier. As patients gain activation, their own searching for information increases [18]. In fact, patients at low levels of activation had learned strategies for self-care from professionals and from trial and error, just as

patients with high activation had done. The difference was that patients with high activation were applying that knowledge consistently. Patients with low activation levels tended to see their low self-confidence about making requests of their physicians, their perceptions of their physicians’ lack of respect for them, and their lack of ability to successfully carry out self-care actions as much more significant barriers.

Patients with low activation scores get significant benefit from both interventions designed to improve their skills at self-care and from interventions designed to improve their self-assertion in interacting with their physicians. This improvement in activation is particularly true of patients whose low activation is combined with passive relational styles in their interactions with their doctors [13]. This group showed the highest increase in activation when they were taught how to formulate questions to ask in their visits with their physicians. In the intervention, interviewers helped patients become aware of common health-related decisions in several domains and brainstormed questions that might help them make the decisions from that list that were relevant to them. Patients practiced prioritizing information and developing questions with the help of the interviewer, and, perhaps most importantly, they were reminded that the questioning they were learning was expected by their doctors and is associated with better health outcomes. In some team-based care settings, one team member is explicitly assigned to help patients formulate questions, and sometimes even role play asking them, before their visits with their doctors [19].

Measuring activation does not distinguish which patients will struggle with certain barriers to self-care [14]. Patients at all levels of activation perceived the symptoms of their illness, such as pain, as barriers to self-care. Many listed multiple drug combinations and the potential side effects as a barrier. Perhaps the most telling agreement about barriers among patients across levels of activation was the report that feelings of stress and depression were significant in impeding their being able to manage their conditions. This finding supports the routine assessment of the “footprint” of the disease and its treatments in patients’ lives as part of deciding what care and what self-care to recommend [20]. It also supports a routine (more than once a year) screening for depression and anxiety for all patients with chronic illness, whether they are highly activated or not.

The authors of the studies of patients with different levels of activation make certain limited recommendations about what can be done to help patients with low activation scores improve the likelihood of their achieving successful self-care. At the same time, they tend to be much less confident about their recommendations for interventions than they are about their research findings. Smith and his colleagues [12] endorse programs that teach these patients to ask better questions and feel more confident in their medical visits [13], but they stress that multifaceted approaches are likely to be necessary to help patients with low activation achieve partnership in decisions with their doctors. Aung and her team [16] offer a recommendation: “The benefits of good quality chronic care can be best seen in patients at low levels of activation, and health care providers should ensure that these patients receive the full range of chronic care including self-management support, follow-up, and care coordination. On the other hand, improving activation in patients may serve as a

safety net when care is deficient” (p. 123). Dixon et al. [14], stressing the importance of building self-confidence, suggest that reminding patients of their past experiences of success in managing their health is likely to be a useful strategy in instilling self-efficacy for new self-management actions in the future (p. 264). It is a strategy that fits nicely with a solution-focused approach to building confidence.

As I look at the research on patient activation and particularly descriptions of patients with the lowest levels of activation, I am drawn back to the picture of the chasm between some patients and their doctors that is the theme of Chap. 5. Activated patients tend to have higher income, be better educated, and have images of themselves as being healthy people. They see partnership with their doctors as a desirable element in their managing any illness and in maintaining their health. They appreciate high-quality care and are likely to act in ways that elicit good care and partnership [18, 21]. On the other hand, they don’t need best practices in order to stay healthy. The picture of patients with very low activation is similar to the picture of complex patients or multiply-disadvantaged patients in Chap. 5. They tend to have low income with lower education levels. Whether they have more chronic illnesses, they experience themselves as less healthy. They are not confident in their dealings with their doctors, and they are very sensitive to whether or not they are being given good care. If they experience their care as of lower quality, they are less likely to take the actions necessary for managing their conditions. They are more likely to experience the asymmetries of power and social status in their relationships with their doctors and to feel that they are treated unfairly by their doctors [18].

Patients designated as complex, or as deprived, or as trauma victims (to a great degree the same group of patients; see Chap. 5) have high rates of depression. Patients found to have the lowest activation meet the same description. Magnezi and her colleagues [22] studied the relationship of patient activation to depression for 278 patients. The participants were recruited from all the adults who visited two participating doctors at each of two primary care clinics during the same 53-day span of time. Patients were given the PAM plus a measure of depression (PHQ-9) and a measure of perceived quality of life (SF-12). The scores on the PAM correlated negatively with the PHQ-9, i.e., the more activated, the less depressed ($p = 0.0001$), and correlated positively with the SF-12, i.e., the more activated, the higher the reported quality of life ($p = 0.0001$). Of the patients who scored at the lowest level of activation, the majority of patients (58%) scored at or above the PHQ-9 threshold of 10, the point at which patients can be expected to meet criteria for a diagnosis of depression [23]. Symptoms of depression can be part of a picture that is also called low activation. Patients who are depressed are less likely to be actively involved in self-care [22]. A group of patients at all of the levels of activation were positive on their depression screen.

The PAM is not a stand-in for depression screening. However, for patients displaying lower activation levels, the possible role of depression treatment should be considered as one way of facilitating activation. Effective activation efforts can also have an impact on lowering depression scores [22]. In this study, of the patients who were identified as depressed by the PHQ-9, 93% said they would like to have

treatment or follow-up for depression in primary care by their family doctor. Depression treatment in primary care by a behavioral health clinician who is part of the same team as their doctor is acceptable to most patients, with or without their doctor prescribing medication treatment (see Chap. 3). This can be a good plan because brief treatments for depression in primary care such as solution-focused therapy [24], cognitive behavioral therapy [25], or acceptance and commitment therapy [26] can all be effective in helping patients become more successful at coping with chronic illness and improving self-care.

The suggestions for interventions with patients identified as having low activation are in line with the emphases so far on empowerment and transparency. Recommendations advise that these patients receive the full array of best practices: care coordination, coaching in how to formulate and ask questions about their healthcare, and efforts to build their self-confidence in relation to their own self-care as well as in relation to their health professionals. These patients need to feel that when they are asking questions or expressing their concerns in the process of their care, they are doing the “right” thing and that their participation is expected and valued. In the rest of this chapter, we will discuss ways of adapting the empowerment approaches described in the last chapter specifically to building the skills and confidence of patients in their roles as patients, as partners with their health professionals, and as self-managers of their health conditions.

9.2 Building Expectations for Activation

The tools of empowerment described in Chap. 8 that can be so effective in building engagement and partnership can be targeted with very minor adaptations toward building patient activation. Adaptation or targeting requires only looking for exceptions, or successful coping, or a vision of a successful future, which are the elements of empowerment, in the specific areas that have been identified as comprising successful activation. Where solution-focused questions look for strengths in any area relevant to the complex problems that multiply-disadvantaged patients face, activation focuses the same techniques on the specific elements that are necessary to successfully manage one’s chronic illnesses in partnership with one’s health professionals.

Interventions targeting the activation level of patients, whatever else they may impact in the way of knowledge or skills or confidence, also involve trying to change expectations. These interventions must change the expectations of patients about themselves and about their health professionals as well as change the expectations of health professionals about the patients. In this case, I am using “expectations” to mean what a person consciously or unconsciously predicts will happen in a situation or relationship, rather than in the sense of “standards” that a person should meet to achieve a goal.

The power of expectations to influence events in relationships has received a great deal of attention in psychology. One of the most famous studies of the power

of expectations was led by Robert Rosenthal [27]. His study tried to assess the impact of elementary school teachers' expectations (predictions) about their students on how well they would learn. The study involved manipulating the expectations of teachers in a way that would not be acceptable in research today. All of the students in an elementary school south of San Francisco were given an IQ test. The teachers were told that it was a special test designed to identify students with previously unrecognized learning potential. A list was given to each teacher of the likely "growth spurters" in their class. The core deception was that this list contained randomly generated names, rather than being based on any results of the test. Their potential "spurters" were just randomly selected kids.

When the IQ test was administered again at the end of the year, the randomly selected students on the list had made nonrandom gains in their IQ scores. The most dramatic gains ("spurters," +27 points; controls, +12 points) were made by students in the first grade. The second grade also showed significant results. In the higher grades, the differences were much smaller or nonexistent. The finding later confirmed in numerous other studies [28] was that enhanced expectations on the part of teachers or therapists or researchers can make significant and sometimes dramatic differences in the performance of students, patients, or research subjects. In the elementary school study, Rosenthal and Jacobson speculated that these expectations were enacted in subtle ways, ways of which teachers tended not to be conscious, and that these subtle changes had very real impacts on students. A change of tone of voice, an expression of optimism that the child could learn a concept or complete a task successfully, a moment of particularly positive focus on a child's success, and likely many other even more subtle manifestations all worked together to influence the child's perception of themselves and to create mutually increased confidence in the child's learning abilities.

The effect of expectations was conceptualized as circular. Others' beliefs about us cause others' actions toward us which reinforce our beliefs about ourselves which influence our actions toward others which impact others' beliefs about us. Rosenthal called this cycle of changing expectations leading to changing behavior leading to changing expectations the Pygmalion effect.

As Rosenthal and others attempted to reproduce the Pygmalion effect, they found that it only worked when the authority was unconscious of having their expectations affected [29]. When teachers or other authorities "acted as if" they had higher expectations, the results were not nearly so positive. The authority had to believe the evidence for the new expectations.

The attenuating of the Pygmalion effect in the upper grades speaks to the difficulty of changing expectations for people who have a history of functioning in a given way. The longer students had been in school, the more time they and their teachers had had to observe their functioning and to form expectations (predictions) about their functioning in the future. A longer history of functioning has more power to keep future expectations constant, though new information, if it is believed, still can make a measurable difference.

In considering how expectations might be relevant for patients with low activation who have complex and expensive health burdens, who are multiply-disadvantaged,

who have long histories of coping with chronic illnesses, and who face behavioral health challenges and other challenges in the area of the social determinants of health, the concept of the impact of attributions can be an important addition. “Attribution” is another way of naming what Rosenthal calls “our beliefs about ourselves,” “others’ beliefs about us,” and “our beliefs about others.”

If I believe that I am a healthy person and that I have a history that shows I can manage my health effectively, I am likely to expect or predict that I will manage my next health challenge effectively. None of this necessarily will be conscious or spoken overtly. It is an assumption about what sort of person I am. It might be what we could call an “implicit attribution” about myself. If my doctor says to me, “I know that this is a challenge for you, but you have always done so well in the past in managing health issues that I expect you will do well this time also,” we might call that an “explicit attribution.” An explicit attribution will be helpful in strengthening my own expectations of my functioning – if I believe it. There, as Hamlet would say, is the rub. If, instead, I think of myself as a sickly person who has difficulty managing health challenges, particularly if I have a long history of struggling with health challenges, and I hear my doctor or other health professional say that they are sure I will do well with the new challenge I am facing, I am likely to find their explicit attribution unconvincing and even alienating. I am likely to experience the positive attribution from the expert who should be helping me as being out of touch with my situation. In addition, if my doctor is expressing expectations (predictions) about how I will do that I believe are unrealistic, it means that either my doctor is poorly informed or is not being truthful with me. Either contributes to my experience of alienation.

We know that in the case of patients with complex health burdens, multiply-disadvantaged patients who are likely to show low activation, doctors tend to change their approach to care, becoming more directive and less partnership oriented [30, 31]. The implicit attribution drawn by patients from such a relationship is that they do not have the knowledge or skills or confidence to manage their conditions. The behavior of their health team implicitly indicates what others think of them. We talked in Chap. 5 about the reciprocal process set up between multiply-disadvantaged patients and their clinicians. These patients who are less healthy are also less likely to engage actively in a visit. They are more likely to internalize stigma about themselves from the implicit attributions they perceive in the care they are given. They need more experiences of support and positive relating than more advantaged, more activated patients to receive the intended benefit from their care. Yet they commonly receive more directive and less supportive care from providers. Health professionals mistakenly assume that these patients are less active in visits because they want less information or care less about their health than more activated patients, making a more directive, less patient-centered approach seem to be best for them. The concept of low activation which fits these patients can become both a cause and an effect in the reciprocal cycle. This is not to suggest that health professionals should act as if they expect patients with low activation to successfully understand and manage their health conditions and their treatments. To do that would be to ask them to be disingenuous with their patients which is unreasonable and possibly unethical.

How can we help the doctor and the health team on one hand and the less activated patient on the other to move beyond this impasse? Let's go back to the discussion about solution-focused interviewing and the neuroscience of memory in Chap. 8. We saw that when a person makes a generalization or an attribution about themselves, based on the episodes they remember, that attribution tends to influence what other episodes can be remembered. People remember events that fit with their current attributions about themselves. When solution-focused questions help the person to notice or discover exceptions to their generalization about themselves, they are often able to remember other events that fit the new pattern, leading to a new implicit attribution that fits the new discovery. This provides new data to modify the expectations of both the patient and the interviewer. Memories of exceptions to problem patterns which provide clear examples of the patient managing better than they or their clinician might have expected offer the possibility of new explicit attributions. The new attributions can be a way of solidifying the impact of the discovery for both patient and interviewer.

Sometimes the new explicit attribution can come from the patient:

Interviewer: When you remember a time like the one you just mentioned, when you handled things well, how does that impact how you think of yourself in this situation?

Patient: I guess I can be more effective than I usually give myself credit for.

Sometimes the attributions can come from the interviewer:

Interviewer: When you remember an incident like this, where you handled things so well, I start to get the impression that you have more ability to handle this problem than you give yourself credit for. Does that sound sensible to you?

Explicit attributions made by the clinician need to be offered tentatively. If a clinician says confidently that the patient has skills or abilities in relation to their health that they have not been aware of, even after a clear exception to the problem pattern has been found through solution-focused interviewing, the statement creates the implicit attribution that the interviewer knows more about the patient than the patient knows about him or herself. This is not a message, no matter how positive it is, that fosters partnership. By offering explicit attributions about a person's commitment, knowledge, or self-confidence in a way that is tentative, the implicit attribution is that the patient is the final arbiter of whether an explicit attribution about them is valid. The interviewer is modeling the same relationship that they would like to encourage, that the patient will be the final decider about their health and healthcare.

The interviewer as well as the patient needs to believe a new attribution when an exception based on solution-focused questioning is uncovered. This is possible when the initial articulation of the attribution is tentative, a trial balloon, for the interviewer as well. When the attribution is thought of as trying out an idea to see if it fits, the tentative formulation is genuine, and, when the patient accepts an explicit attribution based on actual events, both the interviewer and the patient tend to experience that attribution as valid to some degree.

Offering an explicit attribution tentatively requires that the interviewer accepts the patient's judgment about the validity of the attribution without question or

argument. The patient is the best authority about themselves, their actions, and their potential. Offering an explicit attribution can be effective even if the attribution is not accepted at the time. Often, in my experience, a patient denies a positive attribution when it is offered, only to report later that they kept thinking about it and found it useful. Sometimes offering an explicit attribution can start the interviewer thinking differently, even when it is not accepted by the patient. In those situations, the interviewer can maintain an impression, even after agreeing with the patient that it is probably wrong:

Interviewer: When you described how you quit smoking on your own after 15 years of resisting your family’s pressure to quit, I got the impression that you have a determination about you that is powerful. Whether you are determined to do something or not to do it, you make your health actions follow your determination. Does that sound right to you?

Patient: You give me too much credit. I think I just don’t have any will power.

Interviewer: Well, you know yourself better than anyone. I will try to believe that you just don’t have will power, but I can’t promise that I’ll succeed in believing it.

Solution-focused questions and explicit attributions make good pairs. A solution-focused exception question would ask about the times when a patient took specific actions that helped manage their health:

Interviewer: I see that it is very hard for you to get exercise in the face of all the other demands on your time, yet on Tuesday and Friday you somehow managed to take the walk you were hoping to take every day. What was it about those days that made it possible for you to get your walk in, even though I am sure it wasn’t easy?

Patient: I got things cleaned up from breakfast earlier those days, so I had time before I had to go to work.

The patient’s answer then can open an opportunity for an attribution that is a generalization about the patient’s commitment to their health:

Interviewer: When we talk about how you tried to put things together to be able to get in your walk, I get the sense that you have a growing determination to find a way to manage your diabetes better. Does that sound right to you?

Patient: I guess I am thinking about it more these days.

One way of making attributions that are on target for supporting activation is to target the elements of activated functioning in those attributions. Because the concept of activation is based on a hierarchy of beliefs and actions, it provides a pathway for matching solution-focused questions and attributions with the current state of activation that a patient expresses [7]. At the lowest level, questions or attributions would look for instances in which a patient’s statements or actions indicated that they believed in the importance of their role in managing their illness, rather than simply following their health professional’s instructions. This would be discovering that a patient was moving from the lowest level of activation to the second level. In another instance a health professional might highlight an exception or an

example of coping that demonstrated the patient's determination to get the information they needed to do their part in managing their illness. A patient could be observed looking for information on their own, or using information supplied by their health team, or asking more questions and sharing their concerns with their doctor. This would be an example of a patient who was moving from the second to the third level of activation. Finally, a patient might be observed either by what they said or what they did, to be using information that they had gathered, or to be using the habits of self-care they had developed, or to be using their partnership with their health professionals, to maintain their successful management of their illness in the face of particularly challenging life stresses. This would be a transition from level three to level four in the patient activation hierarchy.

While using the levels of activation as a template has been shown to be useful for clinicians, teaching the levels of activation to patients is not likely to be useful. Doing this tends to set up the levels as steps patients are expected to climb, or the level of a patient can become an explicit attribution about them that can tend to fix the patient where they are.

Sometimes attributions are made on the basis of behavior that occurs as part of the relationship with the patient rather than based on solution-focused questioning. These explicit attributions can be a way of defining the patient's behavior differently than the patient expects their behavior to be defined. They can redefine the motivation or the impact of the behavior. These explicit attributions are a way of putting into practice the redefinitions that were part of writing open notes that we described in Chap. 7:

Doctor: Were you able to take the medication that I prescribed last month?

Patient: I picked it up, and I took it a couple of times. I quit because it didn't make me feel any better and I don't like taking more pills.

Doctor: I really appreciate your honesty. When patients are that honest, it makes it so much easier to work together successfully. I also respect your having high standards for your healthcare. Clearly, if something doesn't make a significant difference for you, you are not going to do it just because I recommended it. I agree, you are the one who should be the final decider about your health. Would you like me to go over why I recommended that you take this medicine, or should we drop that subject for a while?

In the list of changes of definition of a patient's behavior for open notes, we suggested that where a health professional might write "failed to take" the medicine, that instead they write "decided against" the medicine (Chap. 7). Here the same change is part of a conversation. The explicit attribution, based on the patient's behavior, is that the patient is actively engaged in their healthcare rather than being uncooperative. In a usual situation in which the patient doesn't take the prescribed medication, the implicit attribution is that the patient is not cooperating and may not care about their health. They have low activation. The explicit attribution above changes the definition of the relationship to one in which the patient is making decisions about their healthcare and cooperating with their doctor by being honest. They are more activated.

9.3 Reasons for Activation

The reasons for patients making health-related changes, i.e., acting in activated ways, are many. Health professionals often expect that managing their illness, maintaining health or functioning, reducing discomfort, or living a longer life are the most important reasons for a patient acting in an activated way. For many patients, these outcomes are valuable mainly as means to other ends. Eliciting the particular reasons that motivate each patient toward self-care can be important so that all team members can use language targeted to what motivates each patient. When asked what makes them work to manage their illness and to stay healthy, many patients report reasons that are about family or values. “I want to be able to spend more time with my grandchildren.” “I want to live to walk my daughter down the aisle.” “I want to take care of this body that God has entrusted to me.” Focusing only on the elements of activation in the PAM can keep a healthcare team from a richer understanding of their patients’ motivations and from discussing considerations that can be especially compelling to each patient.

In order to be sure that some member of the team asks about the particular reasons for managing illness and staying healthy for each patient who shows low activation, it makes sense for the team member in a specific role to have that question assigned. It could be the team member, perhaps care manager, doctor, or behavioral health clinician, who is in a role likely to have substantial contact and to develop a comparatively strong relationship with the patient. The patient’s answers would be shared with other team members. We will discuss this step in more detail in the next chapter.

9.4 An Attribution Generator

Offering explicit attributions is unfamiliar to many health professionals. Their training may well have discouraged attributions. While some psychotherapies suggest using compliments toward the patient [32], explicit attributions can be uncomfortable for those trained not to offer judgments about patients. The exercise outlined below is the one I have used for teaching attributions to all the members of a team. It is somewhat tongue in cheek. Probably no one has the “Attribution Generator” on their wall. The elements are not a prescribed list. The practice, however, is to give health professionals experience in constructing explicit attributions targeted to a specific patient using a tentative formulation, invoking the patient’s reasons for being healthy, and a generalization about their approach to their health that fits with the concept of activation (Table 9.1).

The questions on the PAM can provide ways of formulating the phrases in “C” that are even more precisely targeted to activation.

Table 9.1 Activation script generator: 1 phrase from “A,” then 1 phrase from “B,” then 1 phrase from “C”

A	B	C
It looks to me like...	...you are determined to...	...work on goals to make yourself healthier
I suspect that...	...you are learning to...	...prevent health problems down the road
I may be wrong, but I am thinking...	...your values are helping you to...	...be sure you get the information you need to maintain your health
I get the impression that...	...you are getting more confident that you can...	...follow through on treatments on your own
	...for your sake and for your family, you are going to...	...maintain the lifestyle changes you have made
	...you are getting back on track to...	...get your life back from the effects of your (illness)

9.5 The Team’s Role in Changing Expectations

The focus on finding exceptions, redefining patient behavior, and creating acceptable attributions in the service of increasing patient activation could give the impression that I am recommending that all members of the team add a new segment to the work they already would be doing with a multiply-disadvantaged patient. That is not the case. If the questions and attributions that I am recommending take up significantly more time, they will be impossible to maintain in the long run. No one on the team has time to spare. I can imagine that the patient, as well, would start to wonder about their care if most of their time with their doctor or other team members was taken up with solution-focused questions and attributions.

Team members will use opportunities that come up in the course of their contact with the patient to look for an exception in a pattern of problems or failure. They may articulate a possible new attribution about a patient’s movement toward greater activation and better health. Different team members spend different amounts of time with the patient and have different opportunities for these sorts of questions and observations. Team members will vary in their facility at using this approach. It would be very difficult to characterize a question or an attribution that would be used only by one team member or one role. It is important, however, that as the expectations of the patient begin to evolve through their relationship with one team member, that all team members have access to that information in the medical record as well as in team discussions.

Positive attributions about patients fit well into the practice of open notes and open clinical conversation. Recording an attribution that was accepted to some degree by the patient in a note gives it a bit more reality and likely a bit more impact for patients who read their notes later on. It is in the medical record, in black and white. Such a positive attribution impacts patients’ experience of themselves and their experience of the support and perceptivity of their health professionals. This kind of documentation does not need to be long or detailed:

Note entry: Mr. Jones reports his alcohol intake is down significantly on more than half the days. He agreed with my suspicion that his efforts at improving his health are starting to show results.

This brief note documents an exception that was noted by the patient and his clinician during the visit and briefly refers to the attribution that the clinician offered. This sort of entry might appear in the documentation of the doctor, the behavioral health clinician, or the care enhancer. When other team members mention the attribution that appears in the note to the patient, the reality of team care is brought home to the patient. Changes in expectations of the patient’s potential that emerge from one relationship become reflected in their relationships with other team members. The more a new attribution is discussed and confirmed, the more impactful new expectations are likely to be. Rosenthal’s experiment worked only on the expectations of the authority. Unlike Rosenthal who tried to secretly manipulate the expectations of teachers about students, in patient-centered care in the course of a team working with a patient, the expectations for the patient’s success in managing their health on the part of team members and on the part of the patient can reciprocally evolve.

9.6 Summary

The concept of patient activation is one of an array of concepts designed to help professionals encourage patients, particularly patients with chronic illnesses to be active in caring for themselves. The Patient Activation Measure has proved to do an excellent job as distinguishing which patients are most likely to be successful at self-care. The PAM helps to target specific steps for each patient to help them become more active so they can achieve better health. While the PAM helps identify a group of patients as having low activation, it is a mistake to think of these patients only in terms of their levels of activation. In general, these are the same patients designated as complex and as needing care management [33], as disadvantaged and as needing information targeted to their level of health literacy [34], and as patients with a high likelihood with traumatic experiences as measured on the ACEs screen and needing trauma-informed care [35]. We have used the term “multiply-disadvantaged” to describe this group. Studying the effective approaches in the literature for each group gives options for expanding approaches for patients with low activation. In Chap. 8, we described the elements of trauma-informed care that have been shown to be empowering to these patients. Focusing on strengths and what they do well, called “empowerment” in the TIC literature, can be enacted using the methodology of solution-focused interviewing. In this chapter we have described the way in which a solution-focused approach can be adapted to fostering patient activation. We used the evidence on the impact of changing expectations from Rosenthal’s work on the Pygmalion effect to support an approach that uses mutually acceptable explicit attributions about patients to change the expectation of the patients’ success at self-management on the part of both health professionals and the patients

themselves. In the next chapter, we will focus on ways of using a patient-centered care plan to structure a path to partnership and to better health for multiply-disadvantaged patients.

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Resources

<https://health.ubc.ca/pcpe/projectsactivities/past-projects/talk-your-doc-ttyd> is the address for the listed reference

Patient Activation Measure

Questions of the PAM Short From Permission to Use the PAM

Coaching Patients to Talk to Doctors

“Talking With Your Doctor... and other Healthcare Professionals” by Donald Cegala, MD.

A.C.E Manual for Facilitators, a manual for facilitators for a workshop called “Talking with Your Doctor” for patient groups.

Resources: <https://pcpe.health.ubc.ca/ourwork/ttyd/community>; <https://health.ubc.ca/pcpe/projectsactivities/past-projects/talk-your-doc-ttyd>