

Chapter 10

“M” Is for Mutual



10.1 A Tool for Mutuality

Primary care is a highly organized process, always struggling to balance the need to serve a large number of patients with the need to allow time for the relationships on which successful care is built. For primary care settings to successfully care for patients with chronic illnesses, the patients have to take an active part in the effort. The effort to make patients meaningful members of their own healthcare teams, however, presents a challenge to whatever balance between speed and relating time a particular primary care setting has already achieved. Wherever there is an opportunity to include patients in the standard processes of their healthcare, it makes sense to employ those processes as vehicles for partnership.

The use of open notes is a good example of a standard process in medical care that can promote the patient’s participation on the team. It undoes an often-unnoticed outcome of the usual way of keeping medical notes that every member of the team has access to the notes except the patient. The patient is excluded. Notes are going to be kept on every interaction, and, with some very minor reconsiderations of wording, they can become an important way for patients, particularly multiply-disadvantaged patients, to become better informed about their illnesses and their care and to build trust in their healthcare team (see Chap. 7).

In the first pilot of open notes, the patients who, up to that time had never been exposed to the possibility of reading their doctors notes, were excited by the new option. Once this new channel of communication was opened, patients quickly envisioned what might be considered the next logical step: two-way communication [1]. Sixty percent said that they would like the ability to add comments about the doctors’ notes. In this one area, the doctors, all of whom had volunteered for the program, overwhelmingly disagreed with the patients. They did not want patients’ comments on their notes recorded as part of the medical record, though they were willing to have patients offer ideas or comments to them by secure email. It is impossible to be sure of the specific concerns behind this opinion

because they were not elicited in the survey [1], but we only have to consider the time and energy that might be required of doctors if they had to read and react to new questions relating to their patients’ notes, coming at any point between visits and appearing in the EHR, to understand why the doctors thought this was untenable.

What can we learn from the fact that patients so clearly wanted to be involved in two-way communication about notes? I suspect that the notes, as a core element of the official medical record, have a special status to patients, especially multiply-disadvantaged patients who are likely to experience the providers of medical care as authorities. It is great, as a patient, to be able to see what is being said about you, but it can still feel like you are in a vulnerable or lower position if you have no opportunity to respond to what is said (see Chap. 5). It doesn’t seem to be a partnership.

So far in this volume, we have been working to lay out an approach to serving patients in primary care who have been particularly challenging to engage and help, even for the team-based patient-centered primary care as it is currently practiced. We have described this population of patients for whom these approaches tend not to be fully adequate and sometimes are quite unsuccessful. The population we are describing are patients that are often described as “complex” or high utilizing. A good deal of work has been done to find ways to provide care that improves their health and lowers their cost. These patients are known in other literature as “disadvantaged” patients because they are generally of low socioeconomic status because of their incomes or because of discrimination against their racial group. They are often discussed in literature on equity in healthcare. As Mautner and his colleagues [2] showed, a large percentage of them have histories of trauma and are appropriate for trauma-informed care. We have been using the term “multiply-disadvantaged” to describe this group and the many aspects of their challenges in relation to their health and healthcare.

The patient-centered care plan (PCCP) can be a vehicle for engaging these patients in the creation of a document in their medical record that is a central guide to their own care. Using the PCCP gives the patient a role on their healthcare team and at the same time gives doctors and the health team a way of focusing this important contribution by the patient to a particular time and structured process, a process that can make the patient’s activation toward self-management more likely.

Anyone first encountering the topic of patient involvement in care plans would be justified in being confused by the terms they encounter. The terms “patient-centered care plan” or “person-centered care plan” or “shared care plan” or “collaborative care plan,” any one of which could be designating the kind of document and relational process we are describing in this chapter, are also used in other places to designate other relationships and processes. It is important to distinguish their meaning in each context of their use. Sometimes “patient (or person)-centered care plan” is used to indicate the shift from care plans focused on a particular disease, e.g., a diabetes care plan, to a care plan focused on the array of needs of one patient, particularly when more complete information about their life circumstances or preferences are included. There may be no implication that the patient was involved in the creation of the plan except as a source of information and did not see or approve

the final product. A “shared care plan” can mean that multiple providers are working together to share care of a patient, rather than having each provider operating in a silo. In this use, the term implies that there is a common record of medical history, problem list, medication list, allergies, and so forth and a plan for care to which all providers have access. The same sometimes applies to the use of “collaborative care plan” in which the entities collaborating may be providers in the same health system or a collaboration between medical, mental health, and social service agencies. In these cases, as well, the participation of the patient in the creation of the plan may not be implied. In this chapter we will be focusing solely upon care plans that give the patient a substantive role in creating the plan and regular access to the completed product.

10.2 Role of the Care Plan

The care plan has a long history as a document in inpatient care. It is usually a plan for the nursing care of a patient, sometimes employing subsections of standardized nursing plans for the patient’s individual illnesses or wounds. The Medical Dictionary for the Health Professions and Nursing [3] defines care plan as:

A carefully prepared outline of nursing care showing all of the patient’s needs and the ways of meeting them; a dynamic document initiated at admission and subject to continuous reassessment and change by the nursing staff caring for the patient; typically includes nursing diagnoses, nursing interventions, and outcomes; ensures consistency of care; may be standardized or preprinted.

By this definition, the care plan is a guide for the many nurses and other professionals who will care for a patient during the course of a day and of an inpatient stay. It insures consistency of care by guiding the actions of each health professional.

The care plan was adopted by the American Academy of Pediatrics for its medical home approach for children with complex medical conditions [4]. In this use, it is meant to be a single synthesis of all the relevant information about medical situation and the care of a child. These children are often cared for by several specialists and even several agencies. Having one place, in the primary care pediatrician’s office, where each provider or agency can go to obtain an overall picture of the child’s situation supports coordinated care and spares parents the task of having to be responsible for orienting each new care provider. In this use of a care plan, the expertise of each user is assumed. It is access to the information that improves and coordinates care.

The belief in care plans as ways of informing and guiding practice for high-utilizing patients seems to be growing, particularly in large corporate approaches to care improvement. The demand for plans developed by “experts” has created a growing business. In my research, I found a company that will provide its report on the use of “coordinated care plans,” including a list of potential vendors of plans for different clinical settings, for \$2000. I was not able to learn the cost of the individual plans from the different vendors.

The PCCP adds a new function to the informing and guiding functions that have characterized care plans, that of engaging patients in their care. It creates a process

that requires health team members and the patient to discuss the patient’s preferences and values and record them for use by all. It allows the patient to describe themselves and their social situation in ways that can offer information which team members and other providers can use to guide important decisions in the process of care.

If the discussion of patient values and preferences is framed as a way of helping the healthcare team to understand the patient better, it is particularly engaging for multiply-disadvantaged patients, those with low levels of trust, empowerment, and activation. For a brief time in the process of care, the patient is a consultant to the team about themselves. In my experience, and in the experience of others (Valeras, 2018), this part of the PCCP process gives an opportunity for the team, represented by the member explaining the PCCP to the patient, to express humility in relation to knowledge about the patient and their life. Implying that the team has things they need to learn about the patient in order to do their part of the care better often fits the patient’s experience of what has been a poor fit between themselves and their team up to that point. The information elicited about the patient is aimed at giving the team access to the context for the problem lists that usually are the core information about patients. This gives team members new insights to help them improve their side of the fit. Just the fact that the team wants to obtain the information tends to enhance the patient’s trust and optimism about working with the team. Some of the most noticeable immediate impacts of creating a PCCP can be the improvement of the working relationship between the team and some of their patients who were particularly hard for them to engage.

Team members who might be skeptical about the need for this sort of brief reversal of roles tend to be willing to participate when they observe that the conversation with the patient about their preferences and values can transition seamlessly into a conversation about health goals. Empowerment improves activation (see Chap. 9). Patients who are more activated take care of themselves better, and that makes providing care for them more rewarding.

Adding the engagement function to the care plan through the PCCP inevitably impacts its other functions. The care plan continues to be important in the role of informing health team members and external providers, but it also informs the patient as well. This requires a change in the assumptions about the expertise of those reading the plan. The information in the care plan will need to provide some guidance for team members and other providers on caring for the patient, and it will also be guiding to the patient as a member of the team.

The informing and guiding functions will need to be engaging to team members as well as to the patient. The engagement of the health professionals needs attention, because they may be as untrusting of new efforts that impact their work routines as multiply-disadvantaged patients are untrusting of authorities who want to manage their lives. In order for the PCCP to be engaging to team members, the use of the care plan needs to fit as seamlessly as possible into their clinical practice routines.

Helping with all three functions is, at best, a complex balance that takes determination and creativity for successful implementation. Determination is needed to enlist team members in what will certainly be an inconvenient process at its beginning [5]. Determination is also required to keep the PCCP from being driven out of balance by forces in the health system that want to emphasize guidance of team members in caring for the patient or guidance of the patient in self-management, or increasing the care plan’s role as a repository of clinical information about the

patient. As we look at implementations of the PCCP, the requirement for the balance between the three functions (informing, guiding, and engaging) will help to understand the lack of durability of some these implementations.

10.3 A Brief History of PCCP Trials

10.3.1 *The Shared Care Plan*

The Pursuing Perfection program was a grant program of the Robert Wood Johnson Foundation, with consultation from the Institute for Healthcare Improvement that ran from 2001 to 2008. One of the first grantees was a group from Whatcom County, Washington. Their program strove to make patient-centered care an attribute of the entire county health system, rather than a characteristic of a few healthcare sites. The central tool they developed to help in this effort was the shared care plan (SCP). The SCP was an attempt to involve patients in the creation of a care plan that would inform any medical provider about their medical history, their needs, their social situation, their religion or spirituality, their life goals, and their health goals. When the program was designed, it was expected that any physician would be able to access the care plan electronically at the time of a visit with the patient. The plan template was designed through a process that involved physicians, staff, and patients working with the technical staff of the project. It had tables for capturing complex medical information including the list of medications and instructions for taking each. It listed life goals and short-term goals and had forms for tracking actions for health improvement by the patient in very detailed ways [6].

The design of the program was to help patients in obtaining the information needed to complete the form and in setting health goals. The help came from a “clinical care specialist” who was a nurse or social worker serving as the patient’s health coach and advocate. Then the patient would keep their SCP updated so that any new clinician could be oriented about the patient’s care and the patient’s own health efforts. The original goal was that 70% of patients would have an up-to-date SCP in place at any one time. Ultimately, at the height of the implementation, the percentage of patients with SCPs in place got to just over 40%. Today the program is no longer active, and the website through which patients created and accessed their SCPs has been taken down.

Dr. Bertha Safford is a family physician in Whatcom County who was centrally involved in the creation and implementation of the SCP. She has pointed to several factors that led to the lack of durability of the program [7]. One factor was the inconvenience of the plan for providers. At the time (2001) there was no interoperability between EHRs in the county. Many practices were still using paper records. A provider who was using a computer in a visit would have to log out of the EHR, log into the internet to be able to access a patient’s SCP, and then log back into the EHR. The process could interrupt the flow of the visit and add a few minutes to the total time needed. The lack of interoperability meant that the hope that there could be a cue to the provider in any electronic record about the existence of an SCP for a patient

could not be realized. In the end, SCP was reliably available to providers only if the patient brought a printed copy to the visit.

Dr. Safford believes that the patients on the committee that created a SCP were some of the most activated in the county. Their passion for patient participation was not necessarily shared by the majority of their patient colleagues. They created a form that required extensive information gathering in order for it to be completed accurately. A good deal of ongoing maintenance was required of the patient as they interacted with the health system. When the plan was implemented, the more activated patients who were sick had “too much on their plates” to keep up their SCPs, and the less activated patients, the ones the health system most wanted to reach, never became engaged in the process. The fact that patients were not reliably updating their SCPs meant that a provider who was presented with a copy by a patient had no idea how current the information in the plan was.

The fate of the shared care plan of Whatcom County provides confirmation of the necessity for balancing the informing, guiding, and engaging function of a PCCP. The SCP was created by physicians and patients together and expressed the belief in the power of partnership of both groups, but it was out of balance in that it was not convenient or reliable for providers, and it was not convenient or engaging enough for patients.

In 2012, during my tenure as editor of the journal, *Families, Systems, & Health*, we received two inspiring reports on pilot implementations of patient-centered care plans in primary care settings, one in New Hampshire and one in Seattle. In both cases these implementations were led by clinicians with a commitment to improving the ability of their practices to provide truly patient-centered care. The two programs were similar in many ways, particularly in vision of the potential role of the care plan in patient-centered care. They were different in ways that are instructive about the options and approaches for patient-centered care plans.

10.3.2 Concord, NH

The PCCP in Concord, NH, was developed in a family medicine residency practice serving both rural and urban patients [8]. A significant percentage of patients in the practice would be seen in a federally qualified health center in most cities. The research team consisted of a physician with research experience, a behavioral health clinician with qualitative research experience, two physicians with quality improvement experience, and an outside researcher from a medical school with a national reputation as a center for primary care and behavioral health research. This group designed the PCCP used in the program. The research team in the Concord project was aware of the shared care plan effort in Whatcom County.

The implementation of the PCCP was done by one out of the four healthcare teams in the practice. The team included faculty and resident physicians, medical assistants and nurses, nurse practitioners and physician assistants, and behavioral health clinicians. The care plan had three sections: a medical summary, a “patient snapshot,” and a “goal directed action plan” [8]. The medical summary included a brief medical synopsis or “sign-out,” a problem list with suggested actions,

information on the current continuum of care for the patient, and an emergency plan of action for the patient. The “patient snapshot” included what the patient wanted the care team members to know about them, what the primary care team wanted to communicate about the patient, and information on the patient’s assets, supports, and strengths. The “goal directed action plan” included the patient’s goals and the negotiated action plan with the person responsible for each action. Note that the action plan details steps to be taken by the team members as well as the patient. This was one of the many efforts to create a plan all users would experience as a team agreement rather than as patient instructions. See Fig. 10.1.

Part 1: Medical Summary

Name: <u>Cynthia Brown</u> Nickname <u>Cindy</u> DOB <u>1/1/1967</u>			
Address: <u>11 Pleasant Lane, Apt 3C, Pleasant Town, NH</u>			
Phone # (preferred) <u>603-111-1111</u> (Blocked? Y x N) Best time to reach: <u>5-7 in the evening.</u>			
How do you prefer to be contacted: <u>Phone, but I never answer. I'm the one who checks my voicemail, so you can leave messages</u>			
E-mail <u>n/a</u> Alt. Phone <u>n/a</u>			
Emergency Contact <u>Lucy Brown</u> Phone <u>603-545-4545</u> Relationship <u>mother</u>			
Health Insurance/Plan <u>Medicare</u> ID# <u>VX00111</u>			
Emergency Plan? Y	Advance Directives? N		
Allergies/reaction:			
<ul style="list-style-type: none"> • Lisinopril – angioedema • Bees – hives 			
Medications/dose/purpose:			
<ul style="list-style-type: none"> • Ibuprofen 600 mg four times a day for arthritis • Amlodipine 5 mg at bedtime for blood pressure and migraine prevention 			
PCP <u>Dr. Sally Sunshine</u> Phone <u>603-777-7777</u> Fax <u></u> E-Mail <u></u>			
Care Manager <u>Carol Park</u> Phone <u>603-888-8888</u> Fax <u></u> E-Mail <u>F</u>			
Team RN <u>Jamie Bosana</u> Phone <u>603-888-8989</u>			
Medical Synopsis/Sign-out:			
Cindy has rheumatoid arthritis, s/p hip replacement. She does not drive and was dismissed from her rheumatology practice for no-shows, but they are willing to answer questions about her care from our office.			
Who else is involved in your care? (specialists, nurses, outside agencies)			
#1 Name	Clinic/Hospital	Phone	Other (fax, e-mail, etc.):
Dr. Gupta	Rheumatology	603-999-9999	Release? Y
#2 Name	Clinic/Hospital	Phone	Other (fax, e-mail, etc.):

Fig. 10.1 Patient Centered Care Plan (Concord) (Council et al. [8])

Jay Upton	NH P.T.	603-222-2222	Release? N
#3 Name	Clinic/Hospital	Phone	Other (fax, e-mail, etc.):
Dr. Lee	Orthopedics	603-333-3333	Release? Y

Who are the most important people in your life? (family members, a partner, friends, coworkers, people you live with)	<ul style="list-style-type: none"> • My son, but he is in jail. I miss him. I haven't seen him in 19 months. • My daughter doesn't speak to me. • My best friend is Bonnie. She goes to AA with me. • I also talk to Robert, my minister, every Sunday after church. 		
Who can we talk to about your care?			
#1 Name	Relation	Phone	Other (fax, e-mail, etc.):
Robert Jones	Minister	603-555-5555	Release? Y
#2 Name	Relation	Phone	Other (fax, e-mail, etc.):
Lucy Brown	mother	603-444-4444	Release? Y
Part 2: Snapshot			
<p>Snapshot:</p> <p>What do you want your healthcare team to know about you?</p> <p>(This can include your most important medical and/or emotional concerns. You can also include information about what you like to do in your free time, what you do for work, what your spiritual or religious affiliations are, what your financial situation is, what your unique talents or hobbies are, and what makes you happy.)</p>	<ul style="list-style-type: none"> • I play the guitar. I taught myself. Music is important to me. • I attend church every Sunday. I like going to church, but I'm not religious. • I don't eat meat. • I never have transportation when I need it. I need at least 3 weeks advance notice to arrange a ride, and I don't always know if my transportation is going to show up. • I am quick-tempered, but I don't mean to be. 		
My provider wants my care team to know:	Because Cindy is in active recovery, potentially addictive medications need to be prescribed with a specific plan as to how to take them (e.g., take at 8 am and 3 pm). Always let her know if a medication could be sedating because this makes her anxious.		
<p>Urgent Plan of Care:</p> <p><i>Do you have any recommendations for how your healthcare team should respond if you are in a crisis?</i></p>	<ul style="list-style-type: none"> • If I'm angry, tell me, "Everything is going to be okay." Don't put me on hold. • When I'm in pain, I want to kill myself. When I feel like this, I need a plan. I don't want to be told that you'll call me back. Reassure me the pain is not life-threatening, and ask me if I'm thinking about hurting myself. If I am, help me get in touch with Robert. He always knows what to say. 		

Fig. 10.1 (continued)

Part 3: Action Plan			
Patient goals		Provider goals	
Short-term			
<ul style="list-style-type: none"> • To be able to move like I could before my hip replacement • To stay sober • To be able to visit my son in jail 		<ul style="list-style-type: none"> • Fully participate in physical therapy rehab to achieve maximum mobility post-hip-replacement • Use medications appropriately 	
Long-term			
<ul style="list-style-type: none"> • To become a sponsor in AA 		<ul style="list-style-type: none"> • To decrease use of NSAID medications 	
Negotiated Goal	Action Plan	Person Responsible	Time Frame
1. Do physical therapy exercises at home	Cindy will put pictures of her exercises on her fridge door and do them twice a day	Cindy	Now
2. Re-establish care with a rheumatologist	Care manager will call rheumatology office to see if they will conditionally re-establish care	Carol Park	Within 1 week
3. Attend PT sessions	Ensure transportation to PT appointments	Cindy will reschedule appointments to be before AA meetings, Bonnie will drive to PT appointments and then meetings	Now

Fig. 10.1 (continued)

The Concord PCCP included the patient in defining what information went into it in a way that was a good deal more inclusive of the patient’s perspective than the shared care plan. Unlike some other plans that offer space for only one answer to important patient descriptions, the Concord plan assumes that the patient and their care team might have different perspectives and offers space for both. That frees the patient to answer certain questions from their perspective without requiring that their answer be shaped through a negotiation with a health team member. The result can seem particularly personal, while still reflecting what the patient wants to communicate. It invites a more personal response from any new provider in the patient’s care.

Fully completing the PCCP requires a care management role, whether that is played by a team member designated as a care manager or by another team member. Releases of information, which up to that point had not been needed, have to be obtained. Often multiply-disadvantaged patients are unclear about the details of their care in other settings, who they see and how to contact that person, and the team member in the care manager role makes contacts to clarify. These contacts can include conversations that improve the team’s communication with the patient’s

personal or care networks, a helpful step that also would not have occurred without the PCCP process.

The process of negotiating a PCCP that is as complete as the Concord document takes too much time to be offered to all patients. Usually, a practice would start with a fairly small group until the team is experienced and efficient at their part of the process. Then an expansion of the target group can be considered. In Concord patients to be offered participation in the PCCP were selected at each clinic session in a huddle among the team before the session began. They tended to select patients with complex health pictures who were already requiring significant time and energy from the team and from other parts of the health system such as the emergency department. These were likely to be patients with whom the team did not feel well engaged.

The reports from team members about the impact of the PCCP were very positive. In a residency practice where physicians come and go regularly, they reported improved continuity of care. Physicians reported that this continuity commonly saved doctors who were covering for the patient’s PCP or new residents who were taking over the role of the PCP from ordering unnecessary tests. They judged that the way the plan reflected the patient’s perspective and life circumstances was helpful in establishing rapport and in lowering team frustration when patients did not do what was expected of them. The program was engaging to team members as it developed, because they found that the initial investment of extra time in creating the plan led to less time spent overall on the patients with PCCPs. Nurses who were members of the team reported that the PCCP made it much easier to address patient calls or to respond to a contact from the ED about a patient. Multiple team members described increased job satisfaction as the program progressed.

In several cases, both health team members and patients noticed a lowering of tension or conflict. Patients reported that they felt known by their team and were more willing to work with team members who were not their doctor after the PCCP process. Many said that when they met a new doctor or other team member, they could tell whether the new person had read their PCCP by how they acted. Some patients were proud of the results of the work they had put into their PCCP. They felt new team members should be accountable to have read their plans and told them so.

The PCCP was excellent at building partnership, but it did not impact the ED use of certain patients as much as hoped. Over time, the practice undertook a QI project to further improve the impact on ED utilization for its high-utilizing patients [9]. The unique aspect of the QI project for the PCCP was that every patient who was in the top 5% of ED utilization in the previous year was invited to participate in designing the QI plan. While the group that agreed to participate was small, the impact was substantial. The group met monthly for 6 months. Working with representatives of the QI team, they came up with an addition to the PCCP that specified what both patient and HPs should do when the patient perceived an urgent need for care. The addition in its most recent form [10] was the answers to the questions below (Table 10.1):

Table 10.1 Patient Centered Care Plan (Concord) Urgent Plan of Care

1. Symptoms
(a) What are the symptoms that typically lead to ED visits or frequent calls for perceived urgent healthcare needs?
(b) Why are these symptoms important or worrisome to you?
(c) What has worked for you in the past to address these concerns?
2. Who is on your team?
(a) Who knows you best at the health center?
(b) Who has been most helpful in addressing your concerns?
(c) Who outside of the health center has been most helpful in meeting your urgent needs?
3. Detailed executable plan
(a) What do you want to happen when you have an urgent care need?
(b) How do you want the plan relayed to you (by phone, in person, by whom)?
(c) When would be a good time to check in with you after addressing your urgent need?

During its implementation, there was a significant reduction in ED utilization for the 127 patients originally identified as the high utilizers, both in number of uses and as a percentage of total usage. These patients tended to “rotate off” the high utilizer list and others came on, for whom the urgent plan of care was then offered. Team members tended to exhibit more understanding and tolerance for the patients in the program, which the patients noticed and commented upon. The patients, for their part, were more activated in handling the problems they had previously taken to the ED.

10.3.3 *Seattle, WA*

At about the same time as the Concord effort, a pilot program was developed in the Seattle area [5] built on the work begun in Whatcom County, WA, in the shared care plan. It took a problem-solving approach [11] that focused on helping patients articulate and achieve goals for their health [12]. The designers of the program were particularly aware of the time pressures that face primary care doctors [13] and that negotiating goals might not be part of the training of many doctors [14]. To overcome these barriers, they chose to enhance the role of the nurse/medical assistant using the “teamlet” model of Bodenheimer and Laing [15]. In this model, the medical assistant role is expanded beyond basic collection of information for the doctor, to activities that might be said to “tee up” the content of the patient and doctor visit. Besides taking vitals, the MA in the Seattle program begins the agenda setting for the visit, orients the patient to a discussion about health goals, and often goes through the initial process of setting goals with the patient.

The teamlet approach was chosen so that, as far as possible, the process of creating and the monitoring of the patient’s care plan would be embedded within the routine flow of a clinical visit in primary care. Discussions that in other programs are located in the relationship between the patient and a care manager, or a behav-

ioral health clinician, were streamlined and kept in the patient’s relationship with their MA and their doctor.

The design team met with selected patients and reviewed the literature at the time, and after a great deal of discussion, they settled on a structure for the PCCP that had three sections: “About Me,” “My Goals,” and “My Progress.” As in other PCCPs, the description of the patient that is part of the care plan is from the perspective of the patient (see Figure 10.2, Section A).

Patient-Centered Care Plan

“About Me” (Patient Preferences, Needs, and Values)

Figure 10.2, Section A

- A. I prefer to be called:
- B. I speak (language) as my main language.
- C. I sometimes need help understanding written information about my health (yes/no).
- D. I live with:
- E. I believe the following person(s) in my life are supportive of my healthcare goals:
- F. Religion/spirituality may impact my healthcare in the following way:
- G. My healthcare team and I agree it is important for the people working with me to know the following information (consider working with your MA and provider to fill out this section):
- H. In addition to my healthcare team at family medicine, others important to my care are (e.g., cardiologist, mental health provider, naturopath, or any provider you see regularly):

Name Discipline/specialty Location

- 1.
- 2.
- 3.

This section of the care plan was filled out by the patient on paper before the visit with help, when necessary, from the MA. The copy of the paper document went with the patient into the visit with the doctor and was entered into the EHR later by the MA.

The section called “My Goals” attempts to help the patient define personal healthcare goals in ways that lead to specific actions that can be monitored by the patient and their health team. This PCCP has the process of goal setting built into it in more detail than others. In most cases this process of identifying goals would be started by the MA before the patient met with the doctor. She would orient the patient to the idea of health goals and, using a structured stepwise approach, work with the patient to define at least one goal and actions that the patient could take to begin to move toward the goal. The ideas generated in the meeting with the MA and the patient could be reviewed and endorsed or modified in the patients’ visit with the doctor. In general, the process of finding an overarching goal and breaking it into activities and then specific actions took about 5 minutes for the patient and the MA

to accomplish, once the MA had the experience of a few iterations [16] (Figure 10.2, Section B).

“My Goals” (Personal Healthcare Goals)

Figure 10.2, Section B

These healthcare goals represent what you want to do to live a healthy life as well as the areas of your health that you want to monitor and manage.

1. My healthcare goal #1: (Describe your healthcare goal as specifically as possible as well as why this goal is important to you.)
2. Healthcare goals are most often accomplished by breaking them down into small, specific steps.

My ongoing health activities: What areas do you need help with in order to reach your healthcare goal?

- (a) _____
- (b) _____
- (c) _____

3. There are often several steps to reaching a goal. Consider the options, and choose one of the above areas on which you would like to work.

My ongoing action steps

- (a) What I will do: _____
- (b) How often? _____
- (c) When? _____
- (d) Potential barriers? _____

4. On a scale of 1 (*low*) to 10 (*high*), my confidence in reaching this goal:
5. What can help increase my confidence? _____

The use of the confidence rating comes from motivational interviewing. In some cases, the action which could give the patient more confidence that they would be able to follow through on their ongoing action steps could become an ongoing action step in itself. In cases of a patient having low confidence about achieving the goal, the rating focused the conversation on barriers and kept the conversation from spending time on goals the patient didn’t think were possible.

The “My Progress” section is the monitoring part of this PCCP. Compared to some others plans and to the goals section of this plan, this section is comparatively less elaborated. It offers the opportunity to revise goals as care progresses but doesn’t prescribe the way in with information about the patient’s efforts is collected (Figure 10.2, Section C).

“My Progress” (My Health care Goal Successes and Challenges)

Figure 10.2, Section C

My Healthcare Goal:

Date:

Successes:

Challenges:

Does the goal need to be revised? (Y/N):

The PCCP was offered to patients who had at least one chronic illness that required regular monitoring and who had already established care with the team. The team was made up of four family medicine residents and three faculty, all with part-time clinical practices. The team was supported by one MA, who usually had two doctors seeing patients on any given half day session. All of the doctors and the MA received the same 2 hour training experience in the PCCP process and patient-centered behavior change and viewed a video on negotiating goals. Doctors were given 40 minute visit times with patients who were part of the program and 1:1 support from the MA for the first few visits only. Then they had their usual visit time and the MA supported two doctors.

The program ran for a year. Evaluations at the end identified some consistent experiences among team members. Team members found that allowing time for training and practice was important and that ongoing conversations about the program and about possible refinements were very useful. Training as a team (or teamlet) was very important. While the training they received allowed both members of the teamlet to start using the PCCP, they would have liked more. The process was a new way of interacting with patients, and both doctors and the MA would have appreciated some ongoing reassurance. Both doctors and the MA appreciated the greatly enhanced role of the MA. The PCCP increased continuity of care for the patient among providers within the team. It became a training and a clinical problem-solving intervention for providers and the MA as they gained practice in its use.

Patients tended to report that they felt better known as a person through the PCCP process. They trusted their doctor and the team more and appreciated their doctors taking the time to talk about their health goals. They all were comfortable with the MA talking to them about health goals.

In this implementation, there was a group of patients with low activation (such as multiply-disadvantaged patients) for whom the idea of health goals was difficult. They thought that doing what they were told to do was what was required to manage their chronic illnesses. This confirms the findings cited in Chap. 9 that more activated patients tend to see partnership with their doctor as a value and as part of their managing their health needs, while patients described as at a low level of activation tend to see doing what they are told to do by their doctor as fulfilling the patient’s role in self-management [17]. The emphasis on defining goals and taking the actions needed to achieve them tipped the balance for these patients toward feeling guided rather than engaged by the process. For those people, the engagement function of the PCCP, as it was implemented in the Seattle program, was not adequately realized. This finding highlights the risk of a “health goals” approach rather than a T.E.A.M. Way approach for the multiply-disadvantaged patients.

Ultimately, in both the Seattle and the Concord programs, the accessibility for providers envisioned by the designers of the programs was never achieved. Instead of being immediately available when any provider opened a patient’s record, the PCCP was delegated to the status of “additional documentation” in the EHR. After opening a patient’s record, the PCCP was two or three extra clicks away, and a new user could not always tell that there was a PCCP in place without checking for it. That meant that the plan tended not to be reviewed before each patient visit.

If the PCCP has no utility for the doctor in a patient's visits, over time it gradually loses the organizing and engaging impact that it had when it was being created by the team and the patient. Patients notice the difference, and it can feel like an attrition in the team's interest in their health. It is the PCCP that to them represents their views and suggestions in their medical record. For multiply-disadvantaged patients, that can correlate in an attrition in their efforts toward partnership and self-management that they began to develop during the process of creating their PCCP. The benefits of the creation of the plan, as seen in the increased understanding between challenging patients and their care team and in somewhat lower ED use, then follow the pattern of regression to the mean that happens after the excitement at the beginning of many promising programs.

Perhaps the greatest challenge in trying to achieve a smooth implementation in both the Concord and Seattle programs was the EHR. The EHR was controlled centrally in each health system, as it is in most health systems. The technicians and managers who control these large and extremely complex pieces of software have to address system-wide issues and problems. Because many EHRs are set up primarily to manage types of information needed for billing and for retaining medical data, incorporating a form that was not imagined in the design of the system can require a lot of time and energy, even if the software is able to be adapted to include the new information. Without support and direction from the top levels of the organization, IT departments are unlikely to share the urgency or enthusiasm of the clinical developers for the changes that are required for the PCCP implementation. It is clear that administrative and IT support personnel need to be at the table in the initial development of the project. These people need the time and experience in the project enough to share the enthusiasm and the commitment that tend to grow in the clinicians and patients involved.

In other settings the PCCP has been broadly implemented and is still used. Legacy Health, a large health system serving the metropolitan and suburban areas around Portland, OR, and Vancouver, WA, uses a PCCP for patients who have the services of a care manager [18, 19]. Iora Health is an innovative health system with practices in several areas of the USA. It serves patients on contract to large Medicare health plans. Iora uses a PCCP that doubles as a face sheet for a patient when it is opened by any health team member [20]. These settings have not offered the same level of detail as the Whatcom County, Concord, and Seattle programs partly because they believe that the tools they have developed give them a competitive advantage in the markets they serve.

The patient-centered care plan needs to be a living and evolving record of the evolving relationship between the patient and their healthcare team. We have discussed the impact the PCCP can have on the engagement between the healthcare team and the patient and on healing rifts that may have developed. The increase in continuity of care that has been noted by multiple authors as a result of the PCCP is one element in that improved engagement. The effect of the continuity of relationship, when the health team is using the techniques of empowerment and activation described in Chaps. 8 and 9, usually leads to a changing picture of the patient on the part of the team members. The evolving image of the patient as they become better connected as part of their team should be reflected for the patient and for the larger health system in the PCCP.

10.4 Suggestions for Implementation

The implementations of PCCPs described and evaluated in the current literature cannot be described as more than pilots. The findings, however, when placed in the context of a much larger body of evidence, such as described in the early chapters of this work, allow us to distinguish the outlines of a comprehensive program using patient-centered care plans in primary care. For patients with chronic illness who have moderate to high levels of activation, the Seattle approach to the PCCP, using the teamlet of an MA and a doctor, could help increase their experience of partnership with their doctor and help them work on reasonable, doable goals. In those cases, the emphasis is away from teaching patients and toward facilitating their own decision-making and helping them structure their approach to self-management. It makes shared decision-making a regular part of care rather than a process used only in specific clinical situations. Doctors and MAs who use this approach will require training in facilitation and in goal setting, but this training does not have to be expensive in terms of time spent.

Multiply-disadvantaged patients with complex health needs will require a PCCP approach with more emphasis on engagement, even if that has to be at the cost of the focus on goal setting in the early stages. This was demonstrated by the finding that patients with low activation often do not understand the concepts involved in goals and self-management [5, 17]. For those patients, partnership in defining the treatment plan should be a central feature, so that engagement is more prominent. It is likely that this care plan will need additional staff efforts, either from the care manager or the behavioral health clinician functioning as care manager. Some larger implementations of PCCPs assume that all of the assembling of information and discussing goals with patients will be the province of a care manager on the team [20]. This is thought to lower the inconvenience for doctors and to increase their support for the PCCP process.

The role of patient goals in a patient’s PCCP may evolve over time. Setting health and activity goals for the patient that are judged by the team to be the best for their health may not produce the best-chosen goals from the perspective of long-term values of the patient. We need to face the fact that the steps that a patient might choose to take to begin to be activated as part of their health team might be of negligible value in reducing risks. The wisdom of minimally disruptive medicine [21] is in the choice to define goals that do not add stress on top of the stress patients already experience in coping with their illness burden. Reflecting these more doable goals in the care plan can inform other specialists or services in the health system, to restrain other providers from expecting self-management actions from a patient that are not currently possible for them. The PCCP may also need to evolve because as patients become more empowered, they may learn to ask for and expect better information from their health team, information that should be reflected on the care plan and possibly in new goals. Below is a synthesized example of a PCCP drawn from several of previous plans with some adaptation to fit the T.E.A.M. Way.

Figure 10.2 is an example of a PCCP that incorporates elements from other care plans and adds other elements designed to support the empowerment and activation

Example of a Patient-Centered Care Plan

About Me:

Name: _____ I want to be called: _____ DOB _____

Address: _____

Phone# _____ Best time to reach _____ Can leave a message? _Y_N

Email _____ Alternate phone# _____

Emergency Contact: _____ Phone: _____ Relationship _____

I speak _____ as my main language. I sometimes need help understanding written information about my health _Y_N

My Care Team:

PCP _____ Phone _____ Fax _____ E-mail _____

Care Man. _____ Phone _____ Fax _____ E-mail _____

RN/MA _____ Phone _____ Fax _____ E-mail _____

BHC _____ Phone _____ Fax _____ E-mail _____

Other _____ Phone _____ Fax _____ E-mail _____

Who else is involved in your care? (specialists, nurses, outside agencies)

Name _____ Role _____ Phone _____ E-mail _____ RIs _Y_N

Name _____ Role _____ Phone _____ E-mail _____ RIs _Y_N

Name _____ Role _____ Phone _____ E-mail _____ RIs _Y_N

Who are the most important people in your life?

Who can we talk to about your care?

Name _____ Rel. _____ Phone _____ E-mail _____ RIs _Y_N

Fig. 10.2

Name _____ Rel. _____ Phone _____ E-mail _____ RIs _Y_N

Name _____ Rel. _____ Phone _____ E-mail _____ RIs _Y_N

*What do you want your healthcare team to know about you?
 (This can include your most important medical and/or emotional concerns.
 You can also include information you would be happy to talk with people
 about: what you like to do in your free time, what you do for work, what your
 spiritual or religious affiliations are, what your financial situation is, what
 your unique talents or hobbies are, what makes you happy)*

What my provider wants my care team to know about me:

My Health:

Medical Summary/“Sign-out” by my doctor:

My Medications:

<i>Name</i>	<i>Dose</i>	<i>When (BLDB)</i>	<i>Purpose.</i>

Allergies/reaction:

Advance Directives? _Y_N HC proxy? Name _____ Phone _____

*Things I do to maintain my health (e.g., try to eat a healthy diet,
 try to exercise, try to take my medication as prescribed, check
 myself (weight, blood sugar, feet, others), get doctor check-ups,
 ask for information I need from my doctor, avoid excessive drinking,
 avoid illegal drugs, spend enjoyable time with friends or family, try to
 get enough sleep, build in time to relax and decompress,
 use breathing techniques or mindfulness to calm my body or control pain):*

*Ways the care team has noticed that the patient tries to contribute to their
 own health and healthcare: (e.g., tries to come to appointments on time,
 calls for advice or help before a problem gets too serious, tries to be*

Fig. 10.2 (continued)

honest with team members even if that makes things uncomfortable at times, tries to be supportive of health team members):

Barriers to doing what I want to do to maintain or improve my health (e.g., pain, other symptoms of illness, housing instability, hard to obtain food for healthy diet in my area, no place to exercise, family responsibilities or pressures, difficult to get rides to appointments):

Urgent Plan of Care:

- 1. Symptoms*
 - a. What are the symptoms that typically lead to ED visits or frequent calls for perceived urgent healthcare needs?*
 - b. Why are these symptoms important or worrisome to you?*
 - c. What has worked for you in the past to address these concerns?*
- 2. Who is on your team?*
 - a. Who knows you best at the Health Center?*
 - b. Who has been most helpful in addressing your concerns?*
 - c. Who outside of the Health Center has been most helpful in meeting your urgent needs?*
- 3. Detailed Executable Plan*
 - a. What do you want to happen when you have an urgent care need?*
 - b. How do you want the plan relayed to you (by phone, in person, by whom)?*
 - c. When would be a good time to check in with you after addressing your urgent need?*

My future:

What I am able to do or enjoy at this point in my life when illness or stress doesn't get in the way. Things that I would like to be able to do more often:

Things I would like to be able to do in the future, for myself or for people I care about:

Fig. 10.2 (continued)

My health team’s long-term goals for my health:

Things my health team suggests I consider so I don’t take on too much (e.g., picking one action that does the most for my health with the least change in what I am doing now, not going too fast, only doing what is possible to keep doing over time):

Things I want to start working on for my health now (e.g., reducing a barrier, keeping something going well, improving something) and the first thing I will try to do, when, where, how often:

Things my health team will do to help me (e.g., offer tools for tracking what I do or monitoring my progress, check-in with me, aid me in getting help from other health services or community services, help me talk to my family about how to support my plan):

Fig. 10.2 (continued)

of the patient as part of the team. It elicits goals without using that terminology, and it modifies the goal orientation with considerations of what is possible for the patient to undertake due to the burden of their illnesses. It should fit comfortably with a minimally disruptive medicine orientation for serving multiply-disadvantaged patients. Each practice will choose items that fit for its approach to patient-centered care. It is longer than some others. It will require input from the patient and multiple members of the team. The process of completing it may take multiple conversations at different times. One team member should monitor its stage of completion and discuss (probably in the huddle on the day the patient comes for each visit) what parts of the plan are still to be completed and what parts might need to be reviewed and updated.

In any PCCP implementation, a practice will choose which elements of other PCCPs are best to support their approach to patient-centered care. They will format the plan in a way that is the best fit for their population of patients and to fit the contingencies of their own EHR. Some may find additional efficiencies such as having elements of the PCCP pre-populated from other parts of the record they currently collect. For all of these adaptations, a program will need the support of central leadership in their health system or an EHR that they can modify to their own purposes. The current variability in approaches to the PCCP will be likely to continue until there is a good deal more research in the area.

10.5 Summary

The four parts of the T.E.A.M. Way interact recursively to help a primary care practice implement team-based patient-centered care for high-utilizing multiply-disadvantaged patients. The transparency of open notes and open clinical conversations begins the shift of language toward strength-based descriptions of patients.

Empowerment takes the shift in terms about the patient and begins a process of questioning designed to create a narrative concerning the patient's strengths and successes that begins to build the self-efficacy that patients need for participating as partners in their care. Activation uses attributions to refine and expand the narrative in a way that solidifies the identity of the patient as an active member of their healthcare team and creates mutual self-fulfilling expectations of what the team can accomplish for the patient's health. Mutuality is made official through the patient-centered care plan that is an evolving "official" record of a developing partnership.

In the next chapter, we will discuss ways that a practice might go about training a team to use the T.E.A.M. Way and how it might set up a professional development structure so that it can retain team members by allowing them to advance in their roles and their salaries without having to leave their jobs for schooling.

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