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From Followership to Shared Leadership: The Changing Role of the Patient in the Healthcare Team

Mark A. Clark and Martina Buljac-Samardžić

Carol is a 56-year-old woman, [1] *with ongoing diabetes, who recently underwent treatment for breast cancer at a large urban hospital in Washington, DC (USA). Launched into the healthcare system after a self-exam revealed multiple cysts, Carol readily took direction from the medical staff, following where they led. After surgery, she joined a survivors' support group but hesitated to speak up when the members discussed their treatment. She found it fascinating to listen to others, like Nora, who she probably wouldn't have ever met if they hadn't been part of the group; they traveled in different socioeconomic circles. This type of difference didn't seem so much of a barrier, however, and Carol felt some comfort in hearing stories about how all of the survivors' lives had changed in the healing process.*

M.A. Clark, Ph.D. (✉)
Kogod School of Business, American University, Washington, DC, USA

M. Buljac-Samardžić, Ph.D.
Institute Health Policy and Management, Erasmus University, Rotterdam, The Netherlands

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While patients are unquestionably part of the healthcare equation, their specific roles can and have been viewed in many ways. Patients can be recipients of healthcare, products of the healthcare process, consumers of healthcare, stakeholders in the system, or partners in the experience. While healthcare systems and providers have historically been the major determinant in prescribing this patient experience, changes in the healthcare environment have opened the door for a changing role with increased patient involvement and influence. Medical doctors such as Dave deBronkart and Hunter "Patch" Adams advocate for involving the patient in the healthcare journey and its associated decisions, with the latter stating, "You treat a disease, you win, you lose. You treat a person, I guarantee you'll win" (Binder, 2013).

This chapter explores the changing role of patients in healthcare teams at the intersection of follower-centered leadership (e.g., Uhl-Bien, Riggio, Lowe, & Carsten, 2014) and shared leadership (e.g., Carson, Tesluk, & Marrone, 2007) approaches, offering individual and team-context factors that influence this role. The continued emergence of these theoretical perspectives coincides with a shift in healthcare delivery in many Western and other nations (e.g., Japan), which increasingly calls for proactivity of the patient in managing their medical needs (Thompson, 2007). We see the patient role as emerging from a traditional principal–agent relationship in which a patient (principal) is seen as the recipient of medical decisions and prescriptions made by the caregivers (agent) (Scott & Vick, 1999), toward a relationship between the patient and a team of caregivers, who share complementary knowledge, authority, and responsibility in choices about health services.

The patient role and optimal health outcomes may be similarly affected by attributes of the healthcare system, medical staff, and the patient him/herself, which together determine patient effectiveness as followers who are increasingly likely to share in the leadership of healthcare teams. The roles of a healthcare team include both followership and leadership, with varied members of the team embracing different roles at appropriate times. Good followership not only includes understanding where the team is heading, but also providing both support and clear feedback to other members about decisions and actions that influence the patient experience. This attention to process helps healthcare teams achieve

continual improvement, attuning to the environment (and its resources and challenges), member capabilities, and patient needs.

In this chapter we explore the factors and processes related to shared leadership and followership from the varied contexts of the existing research literature, applying lessons to the healthcare environment. First, we introduce the changing views about the composition of a healthcare team: who is included, and when. Next, we consider how the research perspectives of followership and shared leadership may apply to the roles enacted in these healthcare teams. We then briefly review factors in the team context (within and around the team, including organizational-level factors) and attributes of team members that influence the incidence and effectiveness of followership and shared leadership. We conclude this chapter by offering directions for future research and practice. Our perspective is informed by work with patients in multiple healthcare systems, represented by the vignettes in each chapter section that are drawn from a long-term project with an oncology treatment center.

What Is a Healthcare Team?

The initial diagnosis had been a blur. Carol's world got larger and more confusing in a matter of moments, and new people came into her life. Medical professionals mostly, she presumed, but she didn't always know. She had already gone from GP to specialist in those first weeks, then was passed from nurse to radiologist to surgeon to yet another set of nurses, and she wasn't always certain who was behind the lab coat in front of her. Her husband wasn't much help, between his work and own poor health, but luckily her daughter Sheila kept track for her, mostly by writing notes in an old sketchpad. Carol was grateful; while not everyone in her support group had even the basic level of resources that she had, all of them had access to other help from the hospital. Sheila also worked with the social worker on home–life adjustments and a finance counselor to track what was covered by insurance and what needed payment. The dietitian, Denise, had even arranged for a fitness instructor to lead weekly sessions to bring vigor back to treatment-worn bodies. Carol was continually amazed at how many people had an impact on her recovery and her life beyond.

Healthcare teams include a variety of actors, each of whom may move in and out of the picture over time and situations. Traditionally, a great portion of the research on teams and leadership in the healthcare arena keeps its eye on the core medical staff within a given organization—surgeons, other physicians, and nurses (e.g., Scott & Caress, 2005; Spooner, Keenan, & Card, 1997; Steinert, Goebel, & Rieger, 2006). From a patient's perspective, however, the journey through detection, diagnosis, treatment, recovery, and follow-up care includes a larger set of entities most significantly affecting him or her (Weaver, Feitosa, Salas, Seddon, & Vozenilek, 2013; Wyskiel, Weeks, & Marsteller, 2015). Conceptualizing these entities as part of the healthcare team, including the patient, non-medical informal caregivers (who may be family or friends), technical staff such as radiology technicians, patient advocates, and even healthcare system administration staff, represents a departure from the more traditional focus (Frosch, 2015; Greenfield et al., 2014). These team boundaries may be expanded further by including medical staff of related healthcare organizations (e.g., outpatient nurses, physiotherapist of homecare organizations), as the number of healthcare organizations that a patient encounters tends to increase with the complexity of the disease and age of the patient.

The move from a focus on traditional medical staff to an expanding healthcare team, like the increasingly proactive role of the patient, is a change that is predicated by larger societal trends. Medical advances, healthcare industry complexity, aging populations, resource limitations, increasing access to technology, and informed patients together provide challenges that fundamentally alter healthcare systems. The heights which medical science has reached escalates the need for specialization of medical practitioners (e.g., surgeons, technicians), necessitating the addition of these specialists to teams and increasing the likelihood of involving multiple healthcare organizations (O'Leary, Sehgal, Terrell, & Williams, 2012), along with their administrative support in areas such as finance and facility management. Medical systems are also increasingly cost-sensitive, paying special attention to process efficiencies that may help to reduce the use of their most expensive resources (Peikes, Chen, Schore, & Brown, 2009; Pronovost et al., 2006), opening the door to an augmented role for non-medical specialists and non-employees (e.g., informal caregivers, volunteers).

The need for multiple specialists on the healthcare team, beyond the increased number of technicians operating equipment for medical tests, is exacerbated by an aging population with growing likelihood of co- or multimorbidities, a set of two or more chronic disease states in a single patient (Boeckxstaens & De Graaf, 2011), which require multiple sets of medical professionals who may be distributed over facilities, time, and conditions. For instance, there may be a set of acute care specialists at one stage of treatment who transfer care to a step-down unit, then to outpatient professionals for recovery or palliative care. Lee and colleagues (2016) review a case of a patient with multiple morbidities, whose treatment was through a set of intersecting care units (characterized as a multiteam system, MTS), which had to coordinate their efforts to achieve patient outcomes.

This also has the effect of placing the patient at the center of a system of medical teams, with the accompanying necessity of coordinating how the various entities impinge upon the patient experience. Fortunately, patients and their informal caregivers also have access to technology serving to increase transparency of the medical system, tools to manage the engagement, and better quality information about their own medical condition and treatment options. This information may lead to increased knowledge efficacy, confidence in navigating the healthcare landscape, and engagement with medical entities such as members of the healthcare team. In this way, it can be seen that there are coordination tasks that can be managed by the patients themselves and their non-medical informal caregiver support network. Finally, the movement toward recognition of patient ability and right to own their healthcare experience is in keeping with evolving Western societal and organizational norms of individual empowerment and accompanying reduction in power differential between the insider and outsider of a given system or hierarchical level.

The resulting perspective allows, and perhaps demands, inclusion of the patient, non-medical informal caregivers (who may be family or friends), technical staff, patient advocates, and even administrative staff on the healthcare team, alongside physicians and other medical practitioners, albeit in different roles. Kanfer, Luciano, & Clark, 2015, p. 14526 state that:

> To date, the strongest evidence for the value of teamwork in providing high quality hospital care derives from studies that demonstrate the benefits of

teamwork among frontline workers, including physicians, nurses, and other healthcare professionals. These activities serve to increase a common understanding of patient care, more frequent inter-professional communications and higher levels of coordination of care.

We echo the implicit call for increased attention to factors promoting good teamwork in healthcare, but advocate for expanding the view of who can provide valuable input and influence in the healthcare team, and who qualifies as a team member. Particularly, we believe it necessary to shape and support the patient experience by including their first-hand knowledge of their own condition. In this sense, we believe it to be important to consider the patient as a whole person, including all aspects of their experience, in the process of diagnosis, treatment, recovery, follow-up care, and readjustment to post-treatment life. To this end, we offer simple, functional definitions of a healthcare team and team member:

Healthcare team: The collection of entities that influence patient experience, whether inside or outside the formal healthcare system, within and across multiple units which attend to patient needs relating to health, well-being, and the ability to access health services.

Team member: A person who influences a patient's medical journey, with or without recognized medical knowledge or experience, with or without a formal position in the healthcare system, who is able to contribute to the patient's treatment, experience, well-being, awareness, and access to health services.

In line with these definitions, a healthcare team might consist not only of the traditional medical team of formal caregivers but also the patient and a number of informal caregivers who are not medical professionals. The patient's role on the team is critical, because he or she is able to provide knowledge of his or her own condition and experience with treatment. While some patients' questions and concerns could at times slow down or hinder the recovery process, their perspective is needed as they are the only one with a complete picture of the healthcare journey, interacting with all formal and informal caregivers. Informal caregivers are a

necessary part of the healthcare team in their role of providing physical and emotional support to the patient. Such caregivers, who may include the patient's partner, family member, or friend, may be present at consultations with formal medical caregivers and can thus be a secondary information assessor, a source of emotional support, and perhaps physically assist the patient in daily life tasks. In this way, non-medical informal caregivers are able to contribute to patient experience and well-being, and potentially have a voice in the medical decision-making in support of the patient, including at times of patient incapacity.

It is notable that while these team members may fill various roles, their influence on the treatment process can vary according to the patient's perspective. The contribution of particular team members may also be modified over time, as stages of a disease progress and patient conditions change. As with teams in many types of organizations, there is no requirement for members to be equal in terms of influence or any other particular standard. In the end, team members fulfill specific roles, with varying status and duties, which depend to some extent on one another, in service of the experience of the patient.

Leadership, Followership, and Team Roles

Carol increasingly looked forward to her survivor group meeting each week, and began to think of them as her new group of friends—the "#1 ladies" as they called themselves (even though there had been a few men attending the group from time to time). They bonded through their commonalities of survivorship and their appreciation of their differences—they came from different walks of life, various ethnic and geographic backgrounds, spanned socioeconomic classes, and enjoyed varying levels of health outside of their oncology diagnosis. She even established some real friendships outside of the group. She and Betsy, who lived near her neighborhood, had started walking together once a week. Betsy was one of the older members of the group and had lived in the area all her life. She had several grown children and grandchildren around, but still needed to speak with survivors who could understand her daily challenges.

The group had also started discussing readings, a type of book club based around health—physical, nutritional, and spiritual health—exercising their brains. It came easier to some, but everyone could participate. Denise, the dietitian, started the choice of books, but insisted that the true experts were within the group. So Nora, an active and proactive patient, started bringing the latest articles on treatment to the group sessions for discussion. From a family of African diplomats, Nora was well schooled and curious, confident that she would live a hale life beyond her 52 years, and was ceaselessly cheery.

As already discussed, healthcare teams include a variety of actors, some of whom will move in and out of the picture over time and situations, and each of whom will exert influence of varying intensity and effectiveness on the patient experience. Following the traditional definition of leadership as influence toward organizational goals, in the medical context this influence has often been considered to be unidirectional, from a hierarchical authority to a set of followers (cf. Frosch, 2015; Scott & Vick, 1999), such as, when a medical leader influences patient actions toward specific behaviors involved in, for example, treatment compliance. This tradition of hierarchical leadership may be seen as having a firm basis within the customary relationships in healthcare. One insider has likened the culture of medicine to that of maverick test pilots, where the leaders are high-flying expert surgeons who often resist input from others, or any restriction of their central role in patient treatment (Gawande, 2007). However, as the author points out, the advance of technology and complexity of medical procedures necessitates the spreading of the knowledge base of patient treatment across human and technological support systems.

Such a changing conception of leadership and how it fits into well-run healthcare organizations may be necessary to achieve coordinated healthcare outcomes for the patient, team, and system. This approach may consider leadership to be distributed and coordinated among members of a team, operating through a team process (e.g., DeChurch & Marks, 2006; Zaccaro, 2001) with the goal of coordinating action through an interdependent set of members and components. Increasingly, therefore, there is discussion of sharing this leadership influence with others on the medical team (e.g., Steinert et al., 2006), whether as prescriptive advice or a recognition of the reality of how medical teams function. There is also increased understanding of followership, and its impact on leadership,

through the attributes, behaviors, and social construction (e.g., Kean, Haycock-Stuart, Baggaley, & Carson, 2011; Uhl-Bien et al., 2014).

We believe that application of followership and shared leadership theories to healthcare contexts will increase our understanding of the shift in the role of healthcare team members, particularly the role of patients and their informal caregivers. Perspectives and models of shared leadership and empowering patients have developed relatively independently, but have commonalities that may engender a progressive or temporal process of shifting between roles of follower and leader at appropriate times. To successfully apply these theories and explore their intersection, we must be clear in our descriptions and careful not to blur the useful definition of shared leadership and followership constructs.

Theories on patient empowerment are based philosophically on a view of patients as human beings who have the right and ability to choose by and for themselves. Patient empowerment can be seen as "as a process of communication and education in which knowledge, values and power are shared." Within this interactive process, power is "given by someone to somebody" (Aujoulat, d'Hoore, & Deccache, 2007, p. 15). This requires an intense relationship between healthcare providers and the patient and a shift in the representation of roles.

Shared Leadership and Followership

Shared leadership allows for a shifting distribution of influence from team members operating from multiple status levels without regard to formal roles (Pearce & Conger, 2003). Followership, on the other hand, is a set of roles, behaviors, and outcomes within a co-constructed leadership context (Uhl-Bien et al., 2014). This co-construction could be seen as a form of influence; indeed, other scholars support this idea of followers challenging and co-creating with the titular leaders (Carsten & Uhl-Bien, 2013; Nye, 2002). Good followership, in this vein, not only includes understanding where the team is heading, but also provides support and clear feedback to other members about decisions and actions that influence the team goals (in our context of interest, the patient experience and health-related outcomes).

However, if we argue that followers also impart this type of influence, this argument may blur the useful definition of both the leadership and followership constructs. One way to resolve this is to define followership in terms of compliance behavior in the service of the leader's direction, which we believe is in keeping with the review of Uhl-Bien and colleagues (2014) that allows for a variation of follower types and behaviors, as long as they are considered in relation to the overt leadership structure. Thus, any influence that a follower has on other members crosses the line to shared leadership. Because the same person, or the roles that people play, may shift over time and situations, this demarcation is consistent with both shared leadership and followership definitions.

Shared Leadership and Followership in the Healthcare Context

Applying these models to healthcare contexts, it may be that the prescribed role of the patient is generally seen as a particular point on a continuum. On one end, the patient may be seen as a relatively passive follower, a consumer of medical treatment, or perhaps even a product, with the medical team members operating in a paternalistic role. On the other end of the continuum, the patient shares leadership with the medical team, interacting with potentially differential resources (e.g., perspectives and information) to exude some level of influence of the patient experience. However, as noted at the beginning of this chapter, it is likely that patients, like other healthcare team members, actually shift between followership and shared leadership over time and situations.

It is evident that the traditional model of patient as consumer or product of the medical treatment could be reexamined in terms of potential paths moving between followership and shared leadership, such as through modifying behaviors and expected scripts in relationship to traditional leaders. This relationship and progression to shared leadership roles is moderated at different levels; the extent of opportunity built within the system (e.g., shared purpose of the patient and the healthcare system, mechanisms of social support and voice such as educational programs, time, and continuity); behavior (e.g. patient centeredness,

acknowledgment, relatedness, reinforcing feedback versus resistance); and perception (i.e., implicit beliefs, incremental versus entity perspective) of healthcare providers and those of the patient (i.e., beliefs about mindsets of healthcare actors, attitude).

So, what benefit can be gained through considering patient roles as both followership and shared leadership? Followership is important in that it includes stakeholder perspective and also represents one important factor of what makes a leader—having someone to be led. This is particularly important as patients increase their agency through greater access to pertinent medical information, expanding their ability to exercise choice in their options. Because patients may be closer to the process, in that they are living through the treatment process and thus are a vital source of feedback as to treatment efficacy, including their input in medical decisions may help healthcare teams achieve continual improvement by attuning the environment (and its resources and challenges) and member capabilities to patient needs (Peikes et al., 2009).

Followership Toward Shared Leadership

Followership can be understood through "follower-focused" or "follower-centric" perspectives (Kean et al., 2011). The former explores how following is operationalized and socially constructed by followers, exploring the variation in such behaviors and types (Uhl-Bien et al., 2014). Follower-focused approaches emphasize understanding the ways in which followers collectively construct leadership. Generally, the literature adopts a follower-centric approach by investigating followers' perceptions of their leaders, or asking leaders for their perceptions of followers. However, a focus on the followers can be useful in understanding patient roles on healthcare teams. From this perspective, followers can be said to enact distinctive roles in relation to their leader and team: passivity (rule following), activity (participating, but deferring to the leader's preferences or direction), and proactive engagement (critically engaging, speaking up) (Carsten, Uhl-Bien, West, Patera, & McGregor, 2010). This last role, proactivity, includes the sharing of critical information, which may potentially be very important with regard to patients gaining influence

on the healthcare team, such as providing critical information about their own health or understanding of treatment. Speaking up in this proactive way allows this type of follower to challenge and actually co-create with their leader (Carsten & Uhl-Bien, 2013).

This step from generally active to proactive follower may represent a shift to shared leadership, if the proactive follower's input is influential in the team's direction. Shared leadership at its heart is lateral influence among peers (Cox, Pearce, & Perry, 2003) that emerges as a consequence of internal factors (shared purpose, social support, and voice) and external coaching (Carson et al., 2007). This dynamic process of sharing leadership influence when and where it is needed is generally considered to improve performance toward team goals by encouraging collaboration and commitment (Ensley, Pearson, & Pearce, 2003). Viewed in this way, it seems apparent that the patient and perhaps his/her informal caregivers have a valuable perspective that would potentially add to the set of positive outcomes for a healthcare team, while a failure to include patients could potentially cause healthcare teams to fall short of their potential, especially with regard to aspects of patient care that are more likely to be influenced by patient self-knowledge.

For example, a patient with a chronic disease such as diabetes may, at initial diagnosis, be unfamiliar with the disease state and treatment options, which influence the patient to be more of a follower, with the medical professionals as influential team leaders. After time and experience with the disease, treatment, and changes in lifestyle, including idiosyncratic knowledge of what works in his or her own case, the patient may adopt a more proactive stance, increasingly influencing other healthcare team members. As can be seen, in the experience of a patient in a chronic, relatively stable disease with its associated treatment process, the patient may progress from followership to shared leadership.

There are also opportunities for patients to share leadership in more acute cases, especially early in the diagnosis and when there are well-established treatment options. One such example could include a relatively treatable form of cancer such as breast cancer, where a patient may move quickly to influence the course of treatment taken by the medical professionals, while also leading informal caregivers in their manner of

support. Depending on the progression of the cancer, it is also possible for the patient to revert to more of a follower role at times, such as when treatment causes physical and mental exhaustion or when the condition becomes more acute.

Team Context and Patient Factors

One aspect about her oncology survivor support group that Carol really liked was that each of the members, she believed, could bring her whole self to the group. Carol's "whole self" included not only her status as a survivor and as a patient but also her roles as wife, mother, church member, and member of the community. In group sessions, they could talk about all of those things. It actually helped, she supposed, to have the continual contact with the medical staff, as she was almost surprised to feel so comfortable with coming to the hospital and navigating the system. Even her other appointments were easier now. While sometimes the appointment process for her ongoing diabetes treatment, her oncology follow-up, not to mention her general health exams, could be confusing, she found that her time at the support group made it all a bit easier. She learned from the other ladies, and even from their group readings, at least enough to ask better questions.

There has been increasing interest in human process variables in healthcare, driven by the recognition that factors deriving from the context and from the patient him/herself have a real influence on healthcare coordination, patient well-being, fiscal outcomes, and related performance (Epstein, 2014; Manser, 2009; Peikes et al., 2009; Pronovost et al., 2006). This burgeoning appreciation for such factors comes at a critical junction in healthcare, where increasing complexity of healthcare systems, aging populations, resource limitations, technological advances, and informed patients all provide challenges that compel innovation in healthcare management approaches. Understanding a little about these factors, in an ecological system across people, teams, and organizations (Street, 2003), can provide a basis for configuring their operation in particular settings, prescribing a range of practical roles for patients on the healthcare team. In the section "Team-Context Factors" and in Fig. 4.1, we discuss factors

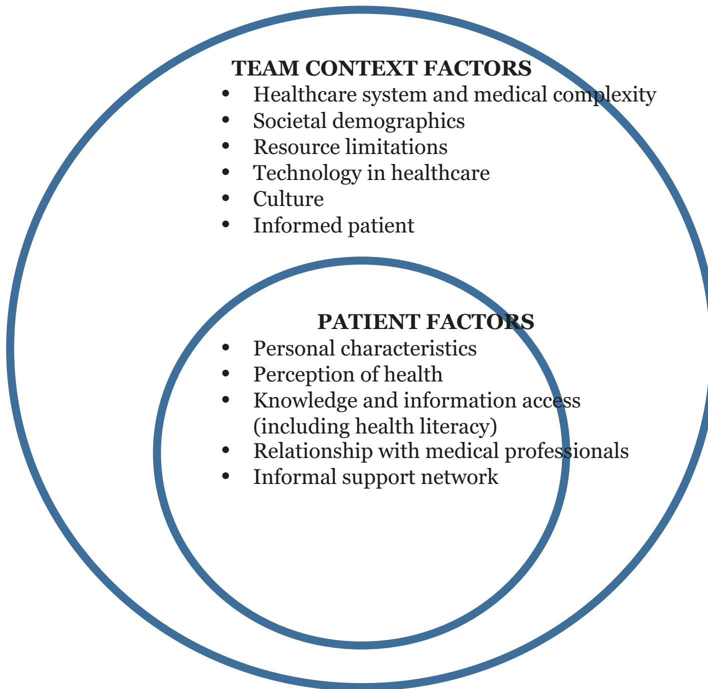

Fig. 4.1 Factors influencing patient role on the healthcare team

in the team context—around and within teams—and at the patient level that influence the role of the patient on the healthcare team, as a follower or in sharing leadership.

Team-Context Factors

Healthcare System and Medical Complexity Medical advances have created opportunities for patients that are both encouraging and complex, and that relate to an aging population with increased need for healthcare. The mortality of some diseases has fallen sharply, such as a 40% drop in deaths from heart attacks and strokes in the UK over the most recent ten-year period, an acceleration of a longer trend (Spencer, 2016). There are healthcare advances in areas such

as targeted antibodies, medical pharmaceuticals, gene therapy, and numerous other medical fields (Gottlieb, 2015); while serving to keep patients alive, this also may mean patients require extended periods of treatment. This extension of treatment and diminishing mortality rate also increases the likelihood of multimorbidity in patients (Koné Pefoyo et al., 2015), while the multiple advances themselves further decrease the likelihood of a medical practitioner being acquainted with developments outside (or even sometimes within) his or her own limited specialty. Together, these often lead to a patient being treated across several separate specialists or medical units, with potential for them to serve as a locus of coordination (Lee et al., 2016).

Societal Demographics Our global societies, particularly but not confined to the Western world, have increasing life expectancy, education, relative wealth, and access to healthcare services (Kena et al., 2016; United Nations, 2015). The medical advances outlined are, naturally, associated with an increase in life expectancy and extended healthy life. This expectancy is part of a general worldwide aging population trend, where both a greater number and proportion of the population are older than in the past. Further, this trend includes a number of the "oldest-old" (i.e., people aged 80 years or older) that is increasing at a rate greater even than the overall trend (United Nations, 2015). This results in more people in need of medical care and connected to healthcare systems. At the same time, societal education levels have generally increased, including country ranges of up to 60% post-secondary degrees in Europe and the Americas (UNESCO, 2016). An educated populace, paired with the increased access to information available in our world, creates both opportunities for and threats to established healthcare practice (Neuberger, 2000; Stokken, 2009).

Resource Limitations The World Health Organization (WHO) estimated that the world will be 12.9 million healthcare workers short by 2035, due to factors such as an aging workforce that is challenging to replace and retain (Campbell et al., 2013). The issues discussed—an aging population and workforce, medical complexity, medical possibilities, and multimorbidity—are among the many factors which converge to limit the

availability of financial, human, and other resources within a healthcare system. Financial resources are, by nature, finite and must be distributed, to some degree, among the increased needs of a growing patient population with multiple disease states. Such resources are used to build and operate facilities, supply medical equipment, pharmaceuticals, and more mundane paraphernalia, as well as to employ the large contingent of medical professionals and support staff that serve patient needs. Beyond the financial influence on staffing, there is also the availability of talent as a limited resource. Whether due to the number of persons in a given geographic area, their proclivity for the prerequisite academic study, or their skill in applying their knowledge, there are typically fewer medical staffers than a patient population could ideally utilize. Those professionals in the system must therefore have their time budgeted and schedules carefully planned to minimize financial impact.

Technology in Healthcare The use of technology impacts multiple points throughout the healthcare system. Increasing sophistication of medical devices abounds, such as electronic health records, e-prescribing, decision support systems, electronic management of chronic disease, bar coding of drugs and biological products, robotic surgical arms for precise pediatric surgery, tailored 3-D printing of replacement body parts, and more. Employing such technology in healthcare has been shown to be beneficial in terms of both cost efficiency and process effectiveness (Anderson, 2007). Technology that moves information is pervasive in healthcare. Increased access and speed of sharing information enables healthcare systems to more easily track patient data in real time as well as to aggregate patient trends. Patients themselves use information technology to access medical information, whether their own specific case notes or more generally acquiring knowledge about their disease and navigating the healthcare system.

Culture Such factors may influence a changing sense of the normative practices accepted in healthcare, whether by medical professionals and support staff or by the patients themselves. As a contextual factor, culture can be a powerful guiding force that outlines key values while prescribing acceptable actions and behaviors. This influence can effect expectations

of who is consulted on issues of medical treatment options, how closely follow-up care must be monitored, and related issues. Culture can vary from organization to organization, as well as from unit to unit within a single organization—such as when hospitals adopt differing norms and practices within departments—and also at societal or national levels. One such example that could affect the patient role on a healthcare team would be the cultural value of power difference, the degree to which status distance is accepted, as popularized by Hofstede (2001). Cultures which expect a high power distance between medical professionals and others may have a more difficult time accepting shared leadership of patients. A further example affecting the patient's role within healthcare is the feeling (by healthcare workers and patients) that it is safe to speak up and voice concerns. Hesitancy to speak up may be strongly influenced by beliefs about team member similarity and status (Goldberg, Clark, & Henley, 2011), and is seen as an important factor with regard to communication errors and safety issues (Okuyama, Wagner, Bijnen, 2014).

Informed Patient These factors create opportunities for patients to become informed about the healthcare system, including about their own medical condition and associated care options. Patients who are thus informed may be more capable, and more likely, to assert themselves. However, both the willingness to become informed and the act of stepping up to share leadership in the healthcare team vary with the particular patient. We believe, based on current research and our own experience with patient populations, that the factors that influence the patient's role can be understood and ultimately influenced, as detailed in the section "Patient Factors."

Patient Factors

There is a growing body of research that considers factors affecting the role of the patient in healthcare contexts (e.g., Street, Gordon, Ward, Krupat, Kravitz, 2005), which can, in turn, be bolstered by a larger collection of work in the social sciences that can offer insights in areas of leadership, teamwork, design thinking, and process factors related to coordination

(Weaver, Dy, & Rosen, 2014). Through this lens, we can learn about factors specific to patients and their roles, gaining insight into moderators of patient engagement with their healthcare team through patient personal characteristics, knowledge and information access, and relationship with the medical team members. These factors, in turn, contribute to the greater context of teams and organizations, crossing levels to build our understanding of effective teams, organizations, and healthcare systems.

Personal Characteristics There is some evidence that personal characteristics associated with lower patient participation in healthcare discussions include patient minority ethnic status, lower age, lower educational level, and lower socioeconomic or societal status (Cegala, 2011; Longtin et al., 2010; Street et al., 2005). However, these studies have not determined whether a match between the patient and members of the healthcare team influences participation; for example, whether it matters if both the physician and the patient were of similar ethnicity. Neither was gender found to be predictive of participation on its own, although there was some suggestion of more likelihood of female physicians engaging in communication practices which encouraged patient participation. There is growing recognition that the social-psychological aspects of the interaction between the patient and medical teams impact on the overall quality of care (Schillinger, Bindman, Wang, Stewart, Piette, 2004). There is also evidence for personal variation in the patient's preferred involvement in decisions about their medical treatment (Degner & Sloan, 1992), regardless of other personal characteristics. For future research and field practice, it may also be useful to identify and test a specific set of personality attributes associated with participation, such as assertiveness, extroversion, cognitive flexibility, and agreeableness, among others.

Perception of Health The relationship between perceived health and health outcomes has also been shown to make a difference to the patient experience in the healthcare process (Idler & Benyamini, 1997). In addition to general perceptions of health, many related factors influence health outcomes, such as mobility, self-care ability, pain and discomfort, anxiety and depression, as well as brain function, including memory, thought, and level of attention. These characteristics may

be mediated through other patient factors, such as active health management, ability to engage healthcare workers, and skill in navigating through the healthcare system.

Knowledge and Information Access, Including Health Literacy There are a number of studies reporting that patient participation in healthcare, such as through discussions and for decisions, is influenced by the access of the patient to appropriate knowledge resources (e.g., Davis, Jacklin, Sevdalis, & Vincent, 2007; Fraenkel & Mcgraw, 2007). One manner of representing this knowledge is through the concept of "health literacy." Defined as "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (World Health Organization, 1998, p. 10), it is seen as an important factor influencing patient participation. Osborne, Batterham, Elsworth, Hawkins, and Buchbinder (2013) summarized a series of studies demonstrating that low health literacy among people with chronic disease states is associated with increased mortality, hospitalization, lower use of preventive healthcare services, poor adherence to prescribed medications, difficulty communicating with health professionals, and poorer knowledge about disease processes and self-management skills.

Thus, health literacy includes the capability of the patient to understand, engage with, and use health information and health services. This includes sufficient information to manage health, actively managing health, social support for health, appraisal of health information, navigating the healthcare system, the ability to find good health information, and understanding health information well enough to know what to do. This information includes not only knowledge of the disease state but also information about members of the medical team and their preferences, as well as specific knowledge of operational steps (Davis et al., 2007). Other significant factors have included the time available and knowledge of patient rights in the healthcare context (Cegala, 2011; Fraenkel & McGraw, 2007). Overall, it is suggested that patients are more likely to be involved, or accepted for involvement, on the basis of their literacy in the content and procedure of medical matters.

Relationship with Medical Team Members and Allied Professionals Several studies have reinforced the notion that patients will have a greater likelihood of participating in treatment discussions if they have a good relationship with the medical professionals on their team and are able to communicate effectively (e.g., Davis et al., 2007; Street, Gordon, & Haidet, 2007; Street et al., 2005). It should be noted that these studies tend to uphold the perspective of the physician or medical team. In other words, if the medical professional believes that he or she has a good relationship with the patient, for instance, because the patient is pleasant, non-contentious, and educated (Street et al., 2007), the professional will encourage involvement of the patient in treatment and related discussions. This and similar evidence (e.g., Cegala, 2011; Longtin et al., 2010; Street et al., 2005) also suggest that the communication style and preferences of the medical professional have a strong influence on whether they encourage or allow patient participation. The implicit beliefs about the patient—whether the medical staff believe the patient to be capable of growth versus simply having limited capacity for understanding (Dweck, Chiu, & Hong, 1995)—can therefore influence factors such as the amount of time and knowledge shared with the patient, and thus affect the likelihood of patient participation, whether as follower or shared leader. This phenomenon may also manifest through interactions with allied professionals in the medical setting, such as financial agents and social workers, who support the patient experience and enact a variable level of knowledge and process sharing with the patient. Similarly, patients' perceptions of the attitudes of the formal caregiver's attitude (beliefs, attitude, knowledge about patient involvement, encouragement for patient participation, appreciation of the patient's responsibility/rights to play an active role in decision-making) may be related to the their willingness to share leadership or otherwise be involved in healthcare team decisions.

Informal Support Network A patient will often rely on others outside of the formal healthcare setting to support their experience. These others may be family members, friends, community allies through a church or support group, or others who provide assistance and succor. As with roles of other healthcare team members, the structure and operation of

informal caregiver network may change over time as patient needs and desires emerge and evolve.

The contextual and individual factors outlined, while generally supported by extant research, do not comprise a definitive and exhaustive set of influences on patient involvement in healthcare teams and processes. Further research is needed to understand how such factors work, separately or together over time, to impact not only participation but also outcomes for patient well-being and healthcare system viability.

Conclusion and Directions

Over time, Carol discovered that working toward a healthy experience for herself required not only a more active approach to using the healthcare system resources, but also realizing that she was more capable than she expected in her ability to organize and understand her conditions and the treatment options available. As she engaged more with her own healthcare experience, she found that medical staff members were more likely to help her with more valuable information about her treatment, and that her own family and friends could use her increased knowledge to better support her. By asserting herself as a capable member of the healthcare team, Carol improved her own patient experience.

Allowing patients to have a voice on their healthcare team—letting them create their preferred path between followership and shared leadership—is a needed and valuable response to changes in the medical field, including information access, resource availability, and cultural expectations across the many layers of our society and its institutions. A vitalization of follower's roles can lead to multiple viable paths, each embodying shared leadership in different ways. In this chapter we explored and illustrated some aspects of the patient role in healthcare teams, with the purpose of extending our understanding of followership and shared leadership to provide the insight needed to empower healthcare actors to best work together for optimal outcomes at the patient, team, and organizational levels.

Our discussion has included factors that influence the role of the patient with and within the healthcare team, relating to team composition, followership, shared leadership, team context, and the patient him or herself. Patient participation depends on a "complex interplay of personal, physician, and contextual factors" (Street et al., 2005, p. 961), and at this point it is not entirely clear which factors are most important for particular patient types, settings, and situations. Some situation-specific factors have been supported as strong predictors of patient participation, such as the medical setting and the physician's communication style. Similarly, some specific patient characteristics are associated with more active participation in healthcare teams, such as a higher level of education and status in a majority ethnic group. Further research is needed.

By outlining the changing role of patients as they follow and lead within healthcare teams, we also must call for continued and evolving research approaches to investigate the phenomenon. Importantly, further research must go beyond medical staff and other healthcare professionals to include direct measures and perceptions of patients and their support network. Researchers should investigate the individual-level factors of a patient which influence their willingness and ability to share leadership and to be good followers. Additionally, increased research attention should be given to the multiple context levels—dyadic relationships, teams, departments, institutions, and networks—that surround the patient and shape their experience.

Orienting toward these outcomes, and understanding how the roles can build toward them, is critical for sustaining the healthcare system. Patients must gain perceptible benefit from their increased investment when engaging the healthcare system. Healthcare teams, including medical staff, need to discern how their evolving role as facilitators and perhaps as health educators allow them to fulfill their professional ethics without overly complicating or interfering with the best quality of healthcare delivery. Organizations must realize practical and financial benchmarks in order to continue their operations. Together, these environmental features will craft the role and interaction of the patient with the medical team. By exploring these theories, stories, and evidence, we hope to contribute to the paradigm shift needed to achieve an appropriate level of followership and shared leadership in healthcare, moving

from traditional approaches that socialize healthcare providers as hierarchical superiors (Anderson & Funnell, 2010), while providing insight into the effects of distributed leadership (DL) at multiple organizational levels (Dinh et al., 2014), with the ultimate goal of improving patient well-being within a sustainable healthcare system.

Note

1. Pseudonyms are used for the patients and caregivers mentioned in this chapter; they were voluntary participants in a confidential interview-based study. Participant release forms are in possession of the first author.

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Mark A. Clark is Associate Professor, Kogod School of Business, American University, Washington, DC. His research centers on team performance contexts, investigating the effects of knowledge configurations, leadership, diversity, and strategic human capital practices. To this end, he has studied teams in a variety of settings, including sailing, surgery, cancer clinics, correctional facilities, political campaigns, and social entrepreneurial ventures. His research has been published in *Group Dynamics*, *Human Resource Management*, *Academy of Management Journal*, *Journal of Applied Psychology*, and other academic outlets, and he serves on numerous editorial boards, including *Leadership Quarterly* and *Small Group Research*. He has more than 25 years of experience in organizational research, workforce analysis, training design, program development and action consulting team training, in corporate, government, and not-for-profit organizations. He earned his Master's degree from Ohio State University and his doctorate from Arizona State University.

Martina Buljac-Samardžić is an assistant professor of Organizational Behaviour at the Institute of Health Policy and Management, Erasmus University Rotterdam, the Netherlands. Her research concentrates on teamwork and team leadership in the healthcare setting. She has conducted research in a wide range of healthcare setting; hospitals, primary care, nursing homes, youth care and facilities for disabled people. Her main research interest is how team features, processes, and leadership relate to team performance in terms of team effectiveness and patient safety. Within her research area, the impact of societal trends in healthcare on teamwork is an important scope. Her work has been published in journals such as *BMJ Quality & Safety*, *Health & Social Care in the Community*, *Health Policy*, and other academic outlets. Her teaching focuses around organizational behavior-related topics in healthcare (e.g. HRM, teams, leadership).