

# Mapping the Patient Journey Across the Continuum: Lessons Learned From One Patient's Experience

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Melanie A Meyer, PhD<sup>1</sup>

## Abstract

Patient-centered care is essential for achieving high-quality and cost-effective health care. This is particularly important for patients with chronic or complex conditions who utilize more health-care services and require comprehensive care coordination. This case report draws on a longitudinal journey map—a valuable tool to capture patient experience and inform the care process—for a patient with multiple chronic conditions who needed a hip replacement. An analysis of the patient journey revealed 3 critical needs for a more patient-centered process: (1) making the patient health goal visible; (2) instigating transparent, shared decision-making; and (3) using a closed-loop communication process. Although key challenges exist, systems can facilitate more patient-centered care enabling health-care organizations to improve the patient experience across the continuum and provide higher quality care.

## Keywords

patient expectations, transitions of care, clinician–patient relationship, patient perspectives/narratives, team communication, patient engagement

## Introduction

Patient experience is integral to patient-centered care and has been positively associated with clinical safety and effectiveness (1) as well as decreased utilization of health-care services (2) and improved health outcomes (3). At the heart of patient-centered interactions are shared information, deliberation, and mind-set (4). Adults with multiple chronic conditions (MCCs; ie, conditions that last a year or more and require ongoing medical attention or limit daily living activities) are the predominant users of health-care services, accounting for over two-thirds of health-care costs (5). These MCC patients must manage high volumes of information, numerous medical appointments, and perform many self-care tasks (6). This case report provides the patient–family perspective via a longitudinal patient journey map for an extended episode of care.

## Description

The patient (to be referenced as AB to maintain confidentiality) is an 80-year-old male with MCCs who had posterior hip replacement surgery due to advanced avascular necrosis. The postoperative period and rehab went well, but after 5 months, AB was re-experiencing right hip pain. After a series

of primary care and pain management appointments, he was referred back to the hip surgeon, who diagnosed a hip infection and loose acetabulum. A needle aspiration confirmed staph infection. To address the issue, the hip prosthesis was removed, and a spacer added, with the goal of doing a second hip replacement surgery after the infection cleared. Over the next 5 months, AB received care across a large range of care settings and had 2 major surgery procedures and 9 care transitions. All of these services were provided by one large health system and its care partners. The patient's 79-year-old spouse, LS, performed the required daily care coordination tasks. Although the time between hip replacement surgeries was 5 months, the complete patient journey extended 21 months.

Figure 1 shows a longitudinal patient journey map for AB, including the sequence of events, patient experience evaluation, and communication patterns. A patient journey

<sup>1</sup> Department of Public Health, University of Massachusetts, Lowell, MA, USA

### Corresponding Author:

Melanie A Meyer, Department of Public Health, University of Massachusetts, Dugan Hall 108, 883 Broadway Street, Lowell, MA 01854, USA.

Email: melanie\_meyer@uml.edu



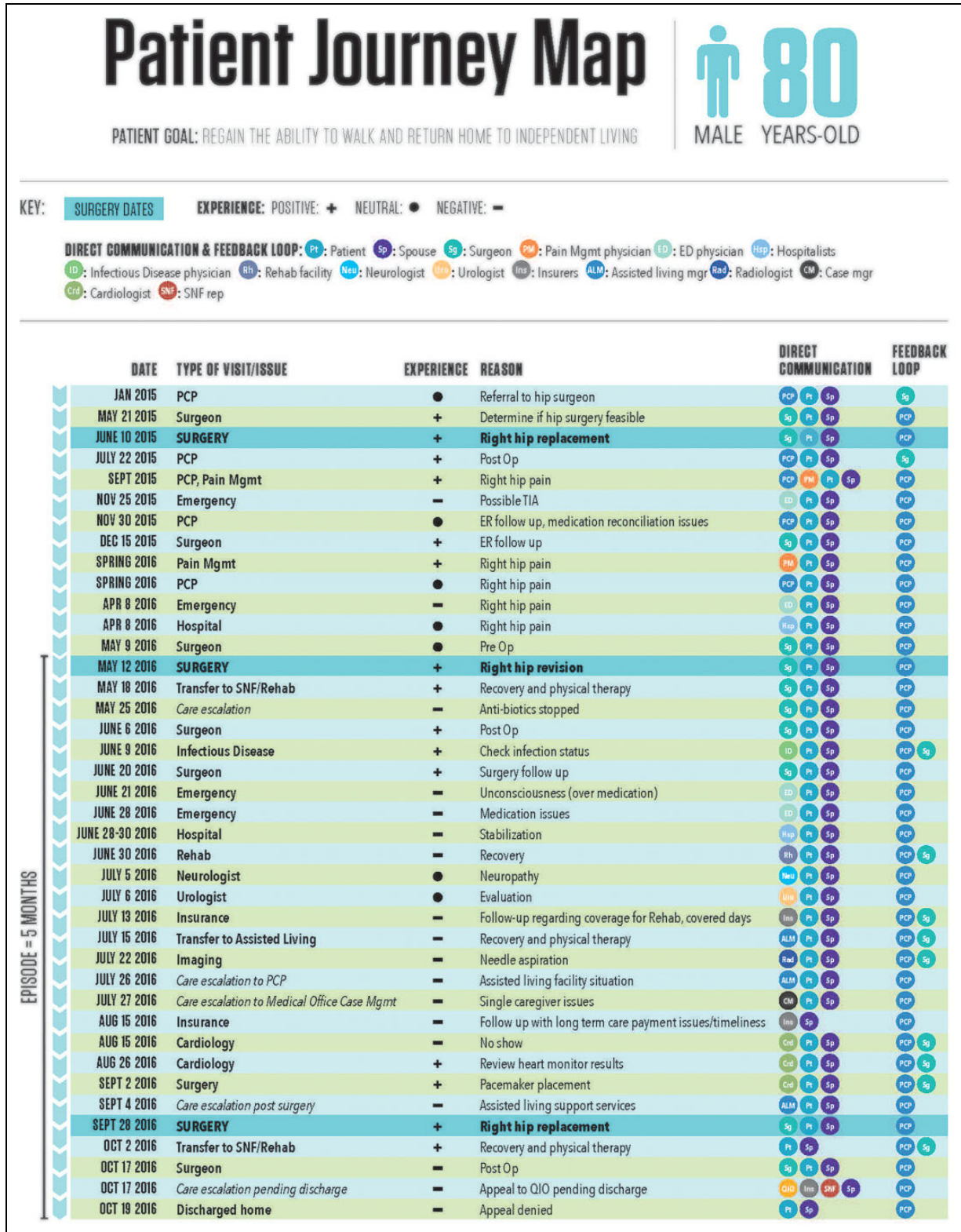


Figure 1. Patient journey map.

map uses quantitative and qualitative data to visualize the patient experience from the patient's perspective (7). Patient journey maps can be generated using a variety of techniques (8,9), can be used to identify problems, and can suggest improvements to the care process (7). The effectiveness of these maps has been researched in a range of care settings, including chronic care (10). As a result of analyzing the patient journey, 3 critical needs were identified: a visible health goal, transparent shared decision-making (SDM), and a closed-loop communication process. These 3 needs are discussed below.

## Results

### *Critical Need 1: A Visible Health Goal*

Patient AB's health goal was to regain the ability to walk and return home to independent living. However, throughout this 5-month care episode, the family had no sense of the health-care organizations managing toward this health goal. For example, when AB needed a heart monitor to assess his heart condition to undergo the second surgery, cardiology front office staff delayed ordering the monitor. Only after spouse LS had contacted them many times and explained the urgent need for the monitor did they respond to her request. Eventually, she picked up the monitor from a supplier and then AB installed it himself. Later, when AB made the transition to assisted living, no services (eg, physical therapy, nursing, and transportation) were established upon the transition. Spouse LS had to initiate contact with the primary care provider (PCP) and the surgeon's office to request these services. Then, the physical therapists were unwilling to commit to a specific visit schedule. Compounding matters, the nurse was a no-show for initial meetings and calls had to be made to reschedule. Throughout these encounters, staff seemed unaware of the patient's health goal. Key questions were raised by the patient and family:

- Did all parties understand the patient's health goal and time frames needed to meet goal?
- Why was there no sense of urgency?

### *Lessons*

These patient experiences highlight the need for a shared, longitudinal care plan that clearly spells out the patient's health goal and serves as a roadmap to reach the best health outcome. This plan should be available electronically to all members of the care team including family members, with specific accountabilities, allowing for asynchronous collaboration and dynamic updates to foster engagement (11,12). From the patient perspective, quality of care means meeting the health goal(s) as quickly as possible. Systems can support shared care planning, thus increasing patient health goal visibility.

### *Critical Need 2: Transparent, SDM*

The benefits of patient-physician SDM have been widely documented (13,14). In this case scenario with AB, however, many actions and decisions did not involve the patient or spouse. First, neither AB nor his spouse was informed whom to contact for specific issues (eg, the PCP or surgeon). Thus, spouse LS was compelled to follow up with both. Second, after the first surgery, AB was transferred from a skilled nursing facility (SNF) to a rehab facility, then within 2 weeks, from the rehab facility to assisted living. Initially, no reason was given for the second transition to assisted living. Only after great persistence, spouse LS was told that it was because her husband was not showing progress toward walking again, and therefore, insurance would not cover costs for his staying at the rehab facility. However, given the fact that AB had just had his hip prosthesis removed, walking was not feasible. Third, after AB had been at the rehab facility for 2 weeks following the second hip replacement surgery, he received notice that he would be discharged home the following day, even though he was not expected to be able to put full weight on his hip for at least another 4 weeks, thus requiring significant daily living support. Little information was shared as to why the discharge was scheduled so soon. Key questions were raised by the patient and family:

- Who was making the transfer or discharge decision and on what basis were care transition decisions made? How could the patient participate in this process?
- How could the patient and family understand the clinical and insurance implications of these decisions?

### *Lessons*

The case of AB exemplifies the need for including the patient and family in care decisions. Health information technology can support real-time communication and information sharing, allowing information to be more readily available and actionable to support quality care. Shared decision-making requires free information flow and transparency.

### *Critical Need 3: A Closed-Loop Communication Process*

Regular care team communication is needed, particularly during an extended episode of care. Closed-loop communication is the process of ensuring all parties involved in patient care, including the patient, consistently receive the same information on a timely basis (15). In the case of AB, serious outcomes were avoided only because of spouse LS's careful oversight of his treatment and regular communication with providers, particularly in several instances where serious lapses in care occurred. For example, while AB was recovering at the first SNF, there were 2 occasions when he became unconscious due to overmedication and had to be rushed to the local emergency department. The second time required hospitalization. On another occasion, spouse LS

discovered critical antibiotics had been discontinued and prompted staff at the facility to contact the surgeon to confirm the need for the prescription. The root cause of these situations was failure to coordinate the patient's medications, in essence, closing the communications loop. A key question was raised by the patient and family:

- How were medications being coordinated across care settings to ensure all care team members had current and accurate information?

### Lessons

In the case of AB, care by the health-care organizations involved was not coordinated. As such, much of the work and oversight defaulted to the spouse who often facilitated the closed-loop communication process (as documented in the patient journey map). This case vividly demonstrates the need for regular communication across settings. Only a systems approach is capable of handling the sheer volume of interactions in an extended care episode ensuring closed-loop communication. Connecting all participants across the care continuum ultimately results in far more efficient, quality care.

### Conclusion

Many thousands of patients, like AB, require hip replacement. Each year, approximately 400,000 hip and knee replacements are undertaken in the United States (16). For US Medicare patients, these procedures are the most common inpatient surgeries and have long recovery periods, costing US\$7 billion for the hospitalizations alone (16). Additionally, 1 in 4 Americans, or 3 in 4 aged 65 and older, have MCCs (17). Certainly, these statistics as well as the examples of failures, inefficiencies, and dissatisfaction in patient AB's experiences highlight the great need for—and potential impact of—patient-centered care across the continuum. Although key challenges exist in terms of aligning stakeholders, establishing accountability, and developing standards, systems can address the 3 critical needs identified to successfully implement a patient-centered process. As demonstrated here, mapping the longitudinal patient journey is a valuable tool to better understand patient experience and inform the process. As health-care organizations continue to strive to deliver greater value, patient-centered care should not be the exception, but the norm.

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### **Author Biography**

**Melanie A Meyer** is an adjunct faculty member at University of Massachusetts, Lowell, teaching in the area of health informatics. She also helps healthcare organizations better utilize technology and data to improve patient experience and deliver higher quality, more efficient care.