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Roles and Role Ambiguity in Patient and Caregiver-Performed Outpatient Parenteral Antimicrobial Therapy

Sara C. Keller, MD, MPH, MSHP [Assistant Professor],
Division of Infectious Diseases, Department of Medicine; Associate Faculty, Armstrong Institute for Patient Safety and Quality, Anesthesiology and Critical Care Medicine; Johns Hopkins University School of Medicine, Baltimore.

Sara E. Cosgrove, MD, MSc [Professor],
Division of Infectious Diseases, Department of Medicine; Faculty, Armstrong Institute for Patient Safety and Quality, Anesthesiology and Critical Care Medicine, Johns Hopkins University School of Medicine.

Alicia I. Arbaje, MD, MPH, PhD [Associate Professor],
Medicine, Director of Transitional Care Research, Center for Transformative Geriatrics Research, Division of Geriatric Medicine and Gerontology, Department of Medicine; Johns Hopkins University School of Medicine, and Faculty, Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore.

Rachel Huai-En Chang, MD, MPH [Research Assistant],
Johns Hopkins Bloomberg School of Public Health.

Amanda Krosche, BS [Research Assistant],
Division of Infectious Diseases, Department of Medicine, Johns Hopkins University School of Medicine.

Deborah Williams, RN, MSN, MPH [Infection Preventionist],
Division of Quality Management, Johns Hopkins Home Care Group, Baltimore.

Ayse P. Gurses, MS, MPH, PhD [Associate Professor]
Armstrong Institute for Patient Safety and Quality, Anesthesiology and Critical Care Medicine, Johns Hopkins University School of Medicine; Associate Professor, Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health.

Abstract

Background: Complicated medical therapies traditionally performed in acute care hospitals are increasingly moving to the home, requiring patients and informal caregivers to perform complicated medical tasks. For example, in outpatient parenteral antimicrobial therapy (OPAT),

Please address correspondence to Sara C. Keller, skeller9@jhmi.edu.

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patients and caregivers perform antimicrobial infusions and venous catheter care. The objective of this study was to characterize patient understanding of patient, caregiver, and health care worker roles in OPAT and barriers to fulfilling these roles, with the goal of understanding how to best support patients and their caregivers.

Methods: We performed a qualitative study using 40 semistructured telephone interviews and 20 contextual inquiries of patients and caregivers performing OPAT tasks. Eligible participants were discharged from two academic medical centers on OPAT. Interview transcripts and notes from contextual inquiry were coded based on a human factors engineering model.

Results: We describe four main roles: communicator, advocate, learner-trainer, and lay health care worker doing "high-skilled tasks." Patients and caregivers experienced role ambiguity around OPAT task performance at the time of hospital discharge. Patients noted that their health care workers experienced role ambiguity as well, especially around who was managing their care. Patients and caregivers used role transitions to achieve workload management, in which patients and caregivers transitioned OPAT tasks or non-OPAT tasks from one person to another.

Discussion: Role ambiguity and role transitions were common in OPAT.

Conclusion: Clear delineation of roles in complicated home-based medical therapies and training of all who may perform these tasks could improve the safety and quality of home-based care.

Keywords

human factors engineering; outpatient parenteral antimicrobial therapy; home healthcare; role ambiguity

Increasingly, patients discharged from acute care hospitals to the home are required to take on complicated medical tasks. Understanding how to best facilitate patient and informal caregiver (typically family members, friends, neighbors, or co-workers) performance of these tasks is essential for ensuring patient safety. In particular, patients self-administering outpatient parenteral antimicrobial therapy (OPAT) at home and their caregivers must master the safe, sterile use of complex medical devices (such as a venous catheter [VC], medication delivery devices [such as infusion pumps], and medication preparation devices [such as mini-bags]).[1] Home infusion therapy patients in general and OPAT patients in particular are at risk for 30-day readmissions, VC complications, adverse drug events, and return of infection.[2–5]

Further complicating performance of OPAT-related tasks, OPAT patients frequently initiate home-based therapy after an inpatient stay. The performance of medical tasks after hospital discharge is challenging for caregivers and patients who are recovering from illness or learning new skills, resulting in errors[6] and nonadherence.[7] In our setting, training in OPAT typically starts with a brief introduction prior to discharge, followed by more formal home-based training in the first day postdischarge, then weekly and as-needed monitoring by home health nurses, and finally physician in-clinic follow-up. Patients and caregivers need to quickly take on roles and responsibilities as care tasks are transferred from hospital providers.[8] Understanding these roles is an important component of improving medication

management at the hospital-to-home transition,[8] and is likely important in improving medical task performance in OPAT.

Role ambiguity adds to the complexity of these medical tasks. Role ambiguity occurs when roles remain without a clear definition of who is responsible for task completion or there is uncertainty about which tasks or responsibilities are part of the role.[9–13] Most descriptions of role ambiguity have occurred among employed workers. It is less clear how role ambiguity may affect complex new tasks carried out in the home (by patients and caregivers) with support from health care providers (such as home health nurses, home infusion pharmacists, and physicians). Role ambiguity may be pronounced when OPAT patients are receiving home health and home infusion services, as there are additional people temporarily involved in the person's care.[14] Role ambiguity may decrease shared situational awareness (a shared understanding of the patient's situation)[15] and lead to repeated or missed tasks, interpersonal conflict, decreased commitment, lower performance, and increased stress.[9–13]

Human factors engineering (HFE) provides a systematic approach to understanding how patients, providers, and elements of a work system interact with one another and can provide guidance on efforts for redesigning the work system to optimize patient safety.[16,17] The objective of this study is to learn how to best support patients and caregivers by characterizing patient understanding of patient, caregiver, and health care worker roles in OPAT and barriers to fulfilling these goals, including role ambiguity.

METHODS

Setting

Patients enrolled in the study were discharged on home OPAT from one of two tertiary care academic medical centers in one American city.[18] These two hospitals discharge patients on OPAT to the care of several different home infusion and home care agencies, one of which is affiliated with the hospitals. Eligible participants were aged >18 years, able to speak and read English, and not in hospice care.

Approach and Sample

We used two data collection approaches: semistructured patient telephone interviews and contextual inquiries of patients and caregivers performing OPAT-related tasks at home (medication infusion, VC care, etc.). Semistructured interviews were performed over the telephone to allow patients who lived far from the hospital (and may have received services from different home infusion agencies or lived in rural settings) to enroll in the study. Contextual inquiry involves researchers observing individuals (here, patients and caregivers) in their work system while they work (here, perform OPAT tasks in the home), and asking brief clarification questions to understand motivations, approaches, rationales, and strategies.[19–21] Contextual inquiries occurred within 2 weeks of hospital discharge,[22] with second visits just prior to completion of therapy for patients on > 4 weeks of OPAT.[23,24]

Patients eligible for semistructured interviews had consented for enrollment in a prospective cohort of OPAT patients between November 2015 and June 2018.[3] Of 395 eligible patients, those interested were asked to participate in a study to improve OPAT quality. Those who

returned written consent forms via mail were contacted by telephone to schedule an interview. Patients eligible for contextual inquiry lived within a 45-minute drive of the two hospitals and were recruited via telephone within 5 days of hospital discharge, with written consent forms completed at the time of the contextual inquiry. Patients were contacted prior to the visit to explain the study. Patients were separately enrolled in the interview or contextual inquiry.

We performed purposive sampling to ensure > 15 patients were selected from each gender, from minority groups, and from unaffiliated home infusion agencies.[25]

Data Collection and Analysis

One of three investigators or assistants (S.C.K., M.K., and A.K.—a physician researcher who manages OPAT, a doctoral-trained medical anthropologist, and a research assistant, all with training in qualitative methods) conducted semistructured interviews over the telephone between November 2015 and June 2018. Interviews took 30 to 45 minutes each and focused on experiences around hospital discharge, learning VC care, steps in performing infusions, impact of the therapy on the patient's life, how to get help, and activities of daily living while on OPAT. Interviews were audio-recorded and transcribed.[18]

Contextual inquiries were performed between May 2017 and June 2018. Within two weeks of hospital discharge, one or two investigators or research assistants (S.C.K., M.K.) observed the patient and/or caregiver performing OPAT-related tasks. They asked brief questions and took handwritten notes describing what they saw and heard from initiation to completion of the task. The first five contextual inquiry sessions occurred with both investigators, as the qualitative methods expert trained the physician researcher. A second contextual inquiry session was conducted near the end of therapy for participants who remained on OPAT for 4 weeks or longer. Investigators asked clarifying questions and took handwritten notes describing what they saw and heard from initiation to completion of the OPAT-related task. In addition, tools, equipment, and physical surroundings were photographed with additional written consent. Each contextual inquiry session took 30 to 90 minutes. The physician researcher did not interview or observe patients in her care.

The semistructured interview and contextual inquiry guides were based on a HFE work system model and piloted among three patients prior to the start of the study (Appendices 1 and 2).[26] We first created a preliminary coding template after two researchers (S.C.K., R.H.C.—physician researchers with training in qualitative methods) had each reviewed the same three randomly selected transcripts and contextual inquiry notes. The two researchers completed coding independently and compared codes. This coding template was revised as subsequent transcripts were reviewed, with changes being applied retroactively.

We performed directed content analysis of the codes.[27] While the overall analysis, including the identification of roles, was deductive and based on the work systems model,[26] we used inductive reasoning in developing additional themes and subthemes that emerged from the codes.[19] These emergent themes and subthemes focused on roles of patients, caregivers, and health care workers in OPAT provision. After ten interview transcripts or contextual inquiry notes were coded, researchers reviewed any new codes used and whether codes coalesced

into themes and subthemes. This occurred until thematic saturation occurred.[28] Analysis was facilitated with NVIVO[R] software (QSR International, Version 11).

The local Institutional Review Board approved this study.

RESULTS

A total of 60 patients participated in the study: 40 in the semistructured interviews and 20 in the contextual inquiry sessions (Table 1). Of those undergoing semistructured interviews, 47.5% (n = 19) were women and 82.5% (n = 33) were white. Of those who participated in contextual inquiries, 40.0% (n = 8) were women, 50.0% (n = 10) were white, and 80.0% (n = 16) had a caregiver present.

Data analysis revealed four categories of roles for patients, caregivers, inpatient and outpatient clinicians, inpatient nurses, clinic staff members, home health nurses, and home infusion staff (Table 2): communicator, advocate, learner-trainer, and lay health care workers performing high-skilled tasks. We then identified barriers to these roles and associated mitigating factors (that is, pre-existing factors that helped mitigate barriers) and patient-identified strategies (that is, actions patients suggested or took to address barriers; Table 3).

Communicator

Role.—The role of communicator requires patients, caregivers, and health care workers to clearly convey concerns and treatment plans to one another. Patients and caregivers became communicators of medical concerns with health care workers.

Barriers, Mitigating Factors, and Strategies.—Role ambiguity presented barriers to communication, particularly between patients and their caregivers and health care workers, as described by patients throughout their OPAT courses. For example, patients and caregivers often did not know who on their health care team should fulfill requests or answer questions. As one patient being treated for an infection of a craniotomy plate said:

> I think it's really important for patients to know who is responsible for what part of their care, because it wasn't really clear to me who … owns my head, my neurosurgeon, my plastic surgeon or the infectious medicine people? I have no idea who to call. (63[WF])

Strategies used by patients and caregivers to mitigate this role ambiguity included having a central contact person, such as a case manager, who could direct them to the proper member of their health care team.

Another barrier to patients and caregivers being communicators was low health literacy. Patients often did not understand medical terms used by health care providers, so they employed strategies such as having a friend or family who worked in health care attend medical appointments as an interpreter.

Patients also perceived that health care workers with communicator roles experienced barriers to communication; in particular, role ambiguity. For example, patients reported that home health staff were often unsure of who was in charge and needed to contact many

physicians for information or orders. If patients did not feel their health care team was communicating with one another, they worried that their care was compromised.

Advocates

Role.—Patients saw themselves, caregivers, and health care workers as taking on the role of advocates—that is, they worked to ensure patients received the appropriate treatment.

Barriers, Mitigating Factors, and Strategies.—Patients and caregivers noted role ambiguity in becoming advocates, as they were unsure how to ask for assistance when faced with novel experiences. Patients and caregivers advocated by setting their own priorities, distributing information, requesting assistance, and ensuring safety, as one patient explained:

> Most people… that I talk to … just assume that the doctors and the nurses know what they're doing. … but there are a lot of times where the doctors and nurses make mistakes or they're in a hurry. And so I would just encourage patients to always… question… always ask." (50^{WF})

Patients also saw health care workers, particularly home health nurses and primary care providers, as advocating for them to get appropriate treatment.

Learner-Trainer

Role.—The role of learner-trainer encompassed teaching and learning about OPAT, why OPAT was needed, and how to perform OPAT. Patients saw themselves and caregivers as the primary learners, but saw themselves, caregivers, and health care workers as trainers as well. The original learner had to help others learn the skills. It was essential that all those performing OPAT-related tasks were not only competent in OPAT tasks but in training others in OPAT.

Barriers, Mitigating Factors, and Strategies.—First, patients and caregivers needed to know what OPAT was, why they needed OPAT, how it worked, and what workload to expect. Understanding the job and workload associated with the daily tasks of managing a VC and administering medications was particularly important, and predischarge ambiguity around the caregiver's role was a barrier. For example, one patient's niece had wanted to help but had believed that a nurse would assist with daily tasks. On learning of the required workload, the niece did not return to the patient's home. "[The patient] reflects that she may have gone to the rehab center instead, had she known how much it involved." (58^{AAF}) Another patient stated that he needed information prior to discharge:

> If they had told me what it was going to be like, [and] show me how to do it before I left the hospital, it wouldn't have been bad. But when I got home, and I wasn't really doing that well, and they said, oh, you're going to have to… do this by yourself. I'm like, no way. I can't do it. … I don't know how to do it, I don't want to do it. (54^{WM})

We also found that in learning how to do OPAT tasks, roles frequently transitioned from one person to another and did not necessarily fit the original plan. Frequently, one person (patient or caregiver) was the original learner even if many (patient and multiple caregivers)

eventually assisted with OPAT. Strategies for learning included taking recordings or notes, having more than one person undergo the learning, or adapting learning from similar prior experiences or from others with prior experiences.

Lay Health Care Workers Performing "High-Skilled Tasks"

Roles.—Patients saw themselves and their caregivers in the roles of lay health care workers as they took on high-skilled tasks required for managing OPAT on a daily basis, such as VC care and medication administration. These are tasks that professional health care workers would have performed in the hospital. Workload management between patients and caregivers became an important part of sharing the burden of care at home.

Barriers, Mitigating Factors, and Strategies.—Patients and caregivers faced constraints that could have affected their ability to undertake tasks. Sometimes these constraints changed over time, such as when a caregiver needed to return to work. Some patients and caregivers also faced physical constraints, such as debility (particularly patients immediately postdischarge), arthritis, or visual problems, or cognitive constraints that could have made tasks difficult for the patient or caregiver to perform.

Whether the patient, caregiver, or both performed an OPAT task depended on the nature of the task and the comfort level, training, availability, and ability of the patient or caregiver. Sometimes the patient performed a task without assistance from a caregiver, even if the caregiver was present. For example, one patient's girlfriend had initially assisted the patient on arrival home, but one week into OPAT, the patient performed all tasks while she read a magazine. Sometimes the caregiver performed all tasks. For example, one patient fell asleep as his sister accessed his VC. Sometimes the patient and caregiver each performed portions of a task, especially if the task had many steps or required manual dexterity or physical strength. Finally, sometimes the caregiver performed most tasks while the patient offered support. For example, one patient's husband performed all tasks, but the patient reminded him of steps.

A strategy for workload management included role transitions. The responsibility for a particular task would transition from the patient or caregiver to the patient or another caregiver and back. Role transitions were common between patients and caregivers, for example, as patients recovered from their illnesses or caregivers had to return to work; and also occurred between caregivers. When this occurred, managing role ambiguity was particularly important. Many managed this role ambiguity by having one caregiver take over all patient care for a period of time: "They did different shifts. …One of my sisters lives [nearby]. My partner and my other sister live [out of state], so they were back and forth. So, whosever turn it was would do it." (59^{WF}) Other caregivers also upended their lives to assist patients, including having patients and caregivers temporarily live together. One patient with two out-of-state daughters had one daughter help during the patient's prior illness, and another daughter move in with the patient during the current illness, bringing along the patient's school-aged granddaughter.

Role transitions sometimes occurred within a single OPAT task (such as initiating an infusion), especially if the task was difficult to complete. One patient's brother opened

packages of supplies while the patient swabbed the hub of the VC. A benefit of this shared task performance was that both the patient and the caregiver gained experience.

However, role transitions could mean that those performing OPAT tasks had different skill levels. As one patient advised, “make sure you have somebody you can count on that can do all these things.” (59^{WF}) To decrease the likelihood of VC complication, one patient had only one well-trained person perform each role. Others suggested the least nervous or anxious person should do OPAT tasks.

Needing additional assistance from caregivers sometimes affected patient–caregiver relationships. This was frequently a positive change in relationships, as patients frequently appreciated their caregivers: “I learned that I had the best caretaker in the world.” (57^{WM}) However, some felt that needing a caregiver negatively impacted their independence: “I don’t like being dependent on other people.” (54^{WF}) At times, needing additional assistance from caregivers led to interpersonal conflict. One patient argued with her husband about whether she should receive OPAT or move into a skilled nursing facility:

> I fought my husband. I said, “I am not going into rehab.” I refused to go. And he said, “Well, I can put you in,” and I said, “don’t you dare,” I said, “it’ll be divorce court, I swear. No. I want to come and go as I please. … No, I’m not going to, I will not even consider it.” So, [my daughter] says, “well, [you] can come [live] here.” (54^{WF})

DISCUSSION

We described four main roles in a highly-complex patient-led home medical task, OPAT (communicator, advocate, learner-trainer, and lay health care worker). We learned that role ambiguity—when roles lack clear definition regarding who is responsible for task completion, or when there is uncertainty about which tasks or responsibilities are part of the role—is common in OPAT.[29,30] Role ambiguity has been described from the perspective of the home care provider,[9,31] but not from the perspective of a patient performing complicated medical tasks.[32] Our study is important as more complicated medical treatments using complicated technologies are moving to the home.

The role of communicator was important in OPAT. Patients perceived role ambiguity on the part of their health care workers. It was difficult to know who managed which aspects of their care, and patients wanted to understand who was in charge. In prior studies, home health staff have been shown to struggle with role ambiguity and physician communication.[31,33] Our study shows that patients also perceived this role ambiguity, and it affected their confidence in their health care teams’ ability to manage their care.[34] A briefing session or other communication processes would give patients, caregivers, and all members of the health care team necessary information to complete tasks.[14,35] Alternatively, technology-based solutions can be developed to facilitate shared situational awareness among patients, caregivers, and health care workers.[36]

Patients and caregivers also had to be learner-trainers. Patient engagement should start in the hospital prior to discharge. Mismatched workload expectations occurred in OPAT and

resulted in information management failures.[37] Patients and caregivers must be fully aware of what abilities and time commitment are required to perform home-based OPAT. Patients also found that instructional materials were not always clear, so training materials that are memorable and usable, such as educational videos developed with a HFE-based risk analysis, could be included.[38,39] Others have suggested simulation training be used to support training.[40] Training should address and mitigate potential errors and failures, such as not understanding the workload and how to share it.

Workload management was a struggle in OPAT. This has been well described by health care workers,[41] for example among nurses in ICUs.[42,43] Here, we showed that patients and caregivers managed the time-intensive and highly skilled work required in OPAT dynamically, based on constraints (such as the need to return to work or other obligations, other caregiving, physical state, or abilities) through transitioning roles and sharing individual tasks.

Meanwhile, in both the roles of learner-trainers and lay health care workers in OPAT, role transitions were a common strategy to mitigate the time required for OPAT. The first person trained in OPAT could have been the patient or caregiver, who then trained, thus becoming a trainer as well. This sharing of the burden between the patient and caregiver(s) has been shown in prior work focused on medication management after hospital discharge.[14,44] Our findings also suggest that all those who may need to be involved in OPAT care delivery be trained. If all those involved in a task could not be known in advance, providing education on how to train others could be part of competency for patients and caregivers. In particular, training typically only occurred with one or two people. If others became involved later, providing training tools (such as checklists) may help them become lay health care workers.

We have performed one of the first qualitative analyses of the work of patients and caregivers in home-based OPAT, a complicated home-based therapy. One prior study in the United Kingdom asked about patient preferences in OPAT, but patients in this study received OPAT in outpatient clinics or had visiting nurses do OPAT-related tasks.[45] We sought to explore a broad range of experiences with OPAT by recruiting those of different genders, races, and using different home infusion agencies. We also used two complementary data collection methods to increase the breadth of the analysis, allowing for triangulation of the results and increasing their credibility.[46] We searched for deviant cases throughout the study.[46]

Limitations

This study had several limitations. It was conducted among patients discharged from two academic medical centers in one city, so generalizability is unclear. We did not include other highly complex medical tasks, as these were outside the scope of the study. The study should be repeated with other OPAT populations and among patients receiving different complicated home-based medical therapies. Our focus was on patients and caregivers and on their activities when home health professionals were not observing their performance; we did not interview other key stakeholders, such as home health staff; observe interactions with home health staff; or enroll patients discharged on OPAT to skilled nursing facilities. We depended on patients to describe the training they received from health care professionals.

We performed semistructured interviews over the telephone to allow for the inclusion of patients who may have lived far from the hospital. In doing so, we may have missed contextual information such as body language, but were able to capture some of this information in the contextual inquiry portion of the study. In addition, fewer members of racial/ethnic minorities were enrolled in the semistructured interviews, possibly related to our attempt to enroll patients in more rural (and less racially or ethnically diverse) areas. However, half the patients enrolled in the contextual inquiries were of racial or ethnic minorities.

This qualitative study is hypothesis-generating using an inductive approach. Related to this, we did not investigate relationships between role ambiguity and patient outcomes, nor did we explicitly investigate the quality of pre-existing relationships or gender dynamics between patients and caregivers. In addition, we may have failed to include one or more roles. For example, coordination has been noted to be an important process in older adults managing medications,[47] but it was not described by patients or directly observed in this study. These factors may be part of the invisible patient work system[48] and deserve more explicit research. We also have not performed member checking of these results as part of the planned research, although we presented results to members of the health system's home care agency's Patient Family Advisory Council.[46]

CONCLUSION

We learned that role ambiguity is common among patients and caregivers in home-based OPAT, as are perceptions of role ambiguity among health care workers. Ensuring that patients understand expectations in home-based OPAT is essential for patients, caregivers, and health care workers. In addition, patients need to feel that members of their health care team are communicating with one another and need to understand who is in charge of their care, demonstrating a need for improved coordination across health systems. As more than one person was involved in the care of each patient, cross-training and shared correct information are important. OPAT is a complicated task, and ensuring adequate training and communication among all involved is important for improving the safety and experience of OPAT—and likely for other complicated patient-led medical tasks in the home after hospital discharge.

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Table 1.

Characteristics of Patients on Outpatient Parenteral Antimicrobial Therapy Who Participated in Semistructured Interviews or Contextual Inquiries

Characteristic or Demographic Variable	Semistructured Interviews: n (%)	Home Visit Contextual Inquiry: n (%)
Female gender	19 (47.5%)	8 (40.0%)
Age (mean, standard deviation)	55.4 (12.5)	52 (14.1)
Race/ethnicity: white	33 (82.5%)	10 (50.0%)
Black/African American	6 (15.0%)	9 (45.0%)
Hispanic	0 (0.0%)	1 (5.0%)
Other	1 (2.5%)	0 (0.0%)
Home infusion agency: affiliated	32 (80.0%)	10 (50.0%)
Presence of caregiver at time of first visit	N/A	16 (80.0%)
Two visits completed	N/A	10 (50.0%)

Table 2.

Roles and Those Fitting Roles in OPAT

Role	Persons in Role	Components of Role
Communicator: Patients, caregivers, and health care workers convey medical concerns and treatment plans to one another.	• Patient • Caregivers • Inpatient physicians • Inpatient nursing • Outpatient physicians • Clinic staff • Home health nurse • Home health staff	• Communicate between patients, caregivers, and health care workers • Determine who performs tasks or manages each aspect of care • Bring patient concerns to health care workers
Advocate: Work to ensure patients receive appropriate treatment.	• Outpatient physician • Patient • Home health nurse • Caregiver	• Navigate health care systems • Make appropriate referrals • Advise when medical attention should be sought • Understand which health care workers to communicate with • Attend clinic visits
Learner-Trainers: Patients and caregivers learn what OPAT is, why it is needed, and how to perform it, then train others.	• Patient • Caregivers • Inpatient physicians • Inpatient nursing • Outpatient physicians • Clinic staff • Home health nurse • Home health staff	• Learn why OPAT is needed • Learn how OPAT is performed • Learn how to perform OPAT tasks • Learn what to expect from OPAT • Correct errors • Explain OPAT to other caregivers • Train others • Calm the patient • Learn hand washing • Learn venous catheter care • Learn OPAT delivery
Lay Healthcare Worker Performing High-Skilled Tasks: Patients and caregivers take on the daily performance of OPAT tasks.	• Patient • Caregivers • Home health nurse • Clinic staff • Outpatient physicians	• Perform venous catheter care • Perform OPAT delivery • Perform dressing changes • Receive supplies • Anticipate equipment needs • Schedule infusions • Prioritize timing

OPAT, outpatient parenteral antimicrobial therapy; Caregiver, informal caregiver; health care worker, professional health care worker.

Table 3:

Barriers and Strategies to Successfully Fulfilling Roles in OPAT

Role	Barriers	Mitigating Factors	Patient-identified Strategies to Address Barriers
Communicator	• Role ambiguity: unclear which health care worker to contact with questions	• Caregiver advocacy	• Have central person to contact who can triage questions • Nurse tells them who to contact • Caregiver determines who to talk with
	• Role ambiguity: patients perceive that nurses are unsure who is supposed to be visiting patient	• Same home • infusion company involved	• Family or friends provides nursing assistance • Having multiple nurses allows different perspectives on patient's condition
	• Difficulties connecting with physicians or nurses around complications	• Personal • relationships with nurses or physicians involved in their care	• Caregivers communicate as form of advocacy • Development of workarounds to reach the physician • Have direct contact to health care provider (cell phone number, text, direct emails)
	• Patient or caregiver does not understand medical terminology	• Experience with health care • Patient engagement	• Find a caregiver who is a health care worker • Caregiver attends physician appointment
Advocate	• Role ambiguity: unsure how to ask for assistance when faced with new experiences or in new health care system	• Physician as advocate • Work closely with PCP • Work closely with clinic staff	• Physician helps navigate other health care systems • Physician advocates for patient at new health care system
Learner-Trainers	• Role ambiguity: unsure what to expect in performing OPAT	• Prior training or experience in infusion therapy	• Referred role of prior experience: adapt training from something similar (such as dialysis) • Reach out to social circle to those with prior experience or cared for friend with same thing • Setting expectations for patient
	• Role ambiguity: Inpatient and home health staff tell the patient and caregiver different things	•	• Setting expectations for patient
	• Role ambiguity: • more than one home health nurse, and	• Nurses ask for help or from each other • Similar policies	• Nursing experience of each adds to the other

Role	Barriers	Mitigating Factors	Patient-identified Strategies to Address Barriers
	different home health nurses tell patient and caregiver different things	• Better rapport with some nurses	• Nurses advise each other when there is uncertainty
	• Patient does not understand their medical condition	• Patient advocacy • Caregiver engagement	• Patient reads about condition or treatment to inform themselves • Caregivers advocate when attending clinic visits
	• Patient or caregiver struggles to remember training	• Prior training or experience in infusion therapy • Intelligence or background of patient or caregiver • Patient or caregiver is a healthcare worker	• Caregivers or patient take notes or pictures or videos • More than one person undergoes training • Adapt training from prior experiences (hemodialysis and experience with VC; patient had been a caregiver in OPAT before; heard about a similar experience of a friend)
Lay Health Care Worker Performing High-Skilled Tasks	• Role ambiguity: • OPAT tasks take time and caregiver has other requirements that conflict with patient care	• Large social circle • Patient learns over time	• Multiple caregivers provide care • Patient and multiple caregivers trade off roles • Patient eventually takes on most roles • Patients need less help as time goes along
	• Role ambiguity: patient struggles to perform OPAT task due to physical condition	• Presence of caregivers	• Home health nurse may provide advice • Caregivers perform task
	• Varying levels of expertise may result in a complication	•	• Only one person does each role to ensure same processes used • Least nervous or anxious person does the task
	• OPAT task difficult to do	•	• Work with caregiver to do a specific task together • Caregivers manage their care (advocate)
	• Interpersonal conflicts	• Importance of a large social circle • Importance of health care workers in their social circles	• Family or friends sacrifice for family • Share the burden of caring for the patient

PCP, primary care provider; OPAT, outpatient parenteral antimicrobial therapy.