

ReCAPs (Research Contributions Abbreviated for Print) provide a structured, one-page summary of each paper highlighting the main findings and significance of the work. The full version of the article is available online at jop.ascopubs.org.

Stanford University School of Medicine, Stanford; VA Palo Alto Health Care System, Palo Alto, CA; and University of Washington School of Medicine, Seattle, WA

Corresponding author: Manali I. Patel, MD, MPH, 875 Blake Wilbur Dr, Stanford, CA 94305; e-mail: manalip@stanford.edu.

Disclosures provided by the authors are available with this article at jop.ascopubs.org.



DOI: [10.1200/JOP.2016.017327](https://doi.org/10.1200/JOP.2016.017327); published online ahead of print at jop.ascopubs.org on February 7, 2017.

Redesigning Cancer Care Delivery: Views From Patients and Caregivers

Manali I. Patel, Vyjayanthi S. Periyakoil, Douglas W. Blayney, David Moore, Andrea Nevedal, Steven Asch, Arnold Milstein, and Tumaini R. Coker

QUESTION ASKED: What do patients and caregivers identify as the most important current gaps in cancer care delivery? What key strategies do patients and caregivers recommend to bridge these cancer care delivery gaps?

SUMMARY ANSWER: Patients and caregivers identified four primary gaps in cancer care delivery: poor doctor-patient communication, insufficient attention to conversations about prognosis, lack of care coordination, and lack of access to care locations. Patients and caregivers identified three practical solutions to improve care delivery gaps: use of nonphysician health personnel (eg, community health workers, patient navigators); more widespread alternative care formats (eg, telephone-based care); and extending community-based care locations (eg, home visits, chemotherapy delivery).

WHAT WE DID: We conducted semi-structured interviews with 75 patients and 45 caregivers nationally to understand challenges in current cancer care delivery and strategies to improve care. Using grounded theory methods, we systematically analyzed and coded patient- and caregiver-interview transcripts using a constant comparative method of qualitative analysis.

WHAT WE FOUND: Patients and caregivers reported consistent deficiencies in cancer care delivery, including poor doctor-patient communication, insufficient conversations about prognosis, lack of care coordination, and challenges in access to care locations. We found that patients and caregivers overwhelmingly supported practical solutions to reduce care

delivery gaps, including the use of non-physician health personnel, alternative care formats, and care delivery in community-based care locations.

BIAS, CONFOUNDING FACTOR(S), REAL-LIFE IMPLICATIONS: In our study, we sought an in-depth understanding of gaps in cancer care delivery from the voices of patients and caregivers. Our sample included a heterogeneous sample of patients and caregivers across the United States. Although our sample size was large enough to reach thematic saturation, we acknowledge that the findings may not be representative of the voices of patients and caregivers in other care settings or outside of the United States. In addition, we also only sampled adult populations and, therefore, our results may not be generalizable to pediatric populations. Furthermore, we recruited only English-speaking participants, and our findings may not be applicable to those patients with limited English proficiency. To our knowledge, ours is the first study to explore patient and caregiver perspectives on cancer care delivery and key strategies to redesign care. Patients and caregivers identified three potential solutions that could close the current gap in cancer care delivery. Our findings can be used to redesign cancer care delivery to promote patient-centered, family-oriented care. The findings are a rich reflection of patient and caregiver perspectives and can ultimately lead to innovations that can improve patient and caregiver experiences with cancer care. **JOP**

Redesigning Cancer Care Delivery: Views From Patients and Caregivers

Manali I. Patel, Vyjeyanthi S. Periyakoil, Douglas W. Blayney, David Moore, Andrea Nevedal, Steven Asch, Arnold Milstein, and Tumaini R. Coker

Stanford University School of Medicine, Stanford; VA Palo Alto Health Care System, Palo Alto, CA; and University of Washington School of Medicine, Seattle, WA

Abstract

Introduction

Cancer is a leading cause of death in the United States. Although treatments have improved, patients and caregivers continue to report significant gaps in their care. The objective of this study was to examine the views of patients and caregivers on their experiences with current cancer care delivery and identify key strategies to improve the delivery of care.

Methods and Materials

Semistructured interviews were conducted with 75 patients and 45 caregivers across the United States. The interviews were recorded, transcribed, and analyzed using constant comparative method of qualitative analysis.

Results

Participants reported multiple gaps in care delivery, including barriers in health communication with health care providers, lack of elucidation of care goals, lack of care coordination, and challenges in accessing care. Participants identified that greater use of nonphysician providers and alternative formats, such as telephone-based care and home and community-based care, would narrow these gaps.

Conclusion

Understanding patients' and caregivers' experiences with gaps in cancer care delivery can inform cancer care delivery redesign efforts and lead to targeted interventions that result in patient-centered and family-oriented care.

INTRODUCTION

This year, 1.6 million people in the United States will be diagnosed with cancer, and an expected 500,000 will die of the disease.¹ Although cancer remains one of the leading causes of disease and death, many patients and their caregivers continue to lack critical services. Although laudable efforts are under way to promote personalized cancer treatment, large gaps in care delivery remain, including accurately educating patients regarding their prognosis²⁻⁶

and self-management of symptoms.⁷⁻⁹ In addition, there is opportunity to improve navigation and psychosocial support.^{10,11} Furthermore, these care delivery gaps are more pronounced for vulnerable patient populations.¹²⁻¹⁴

Care delivery innovations can improve these deficiencies. The oncology patient-centered medical home, for example, improves care effectiveness and efficiency.^{15,16} Other efforts, such as the Oncology Care Model, financially reward delivery of

ASSOCIATED CONTENT



See accompanying editorial on page 217



Appendix & Data Supplement
DOI: 10.1200/JOP.2016.017327



DOI: 10.1200/JOP.2016.017327;
published online ahead of print at
jop.ascopubs.org on February 7, 2017.

coordinated, high-quality cancer care.^{17,18} We similarly proposed solutions to improve care delivery that include (1) enhancing the provider-patient relationship through use of alternative staff (eg, lay health workers) to provide services; (2) providing services in alternative formats (eg, via phone); and (3) providing services in community locations outside of the clinical setting.¹⁹ Despite the growing need for cancer care redesign, there is little research in this area. To our knowledge, no study describes patients' and caregivers' perspectives on how to best redesign cancer care delivery.

The goal of this study was to explore the perspectives of a diverse sample of patients and their caregivers on the current state of cancer care and identify key strategies to redesign care delivery. The study was framed by the Quality-of-Care Framework by Donabedian,²⁰ which outlines three criteria to improve the quality of care: structure, processes, and outcomes. On the basis of this conceptual framework, our aims were to assess patient and caregiver views on care delivery and their acceptance of novel ways to expand care services, including delivery by nonphysician providers, non-face-to-face formats, and care provision in home- and community-based locations.

METHODS AND MATERIALS

The study was conducted across five US sites: three large, private oncology practices (one in the Northwest, one in the Southwest, and one in the Midwest) and two large academic cancer centers (one in the Southwest and one in the Northeast). Adult patients (> 18 years of age) who had received cancer care for ≥ 3 months and within at least 1 month of the study (to ensure sufficient personal experience with cancer care) and their caregivers were eligible to participate. Recruitment strategies involved (1) mailings to oncology providers asking them to refer patients and caregivers who met inclusion criteria; (2) waiting- and reception-room flyers; and (3) mailings to 275 randomly sampled households asking interested patients and caregivers (family members, caretakers, or other support) to contact the principal investigator.

Patients and caregivers who met inclusion criteria received information about the study's purpose and time commitment and were invited to participate in a 60-minute interview. On consent, two investigators (M.P. and D.M.) conducted each interview using a semistructured interview guide (Appendix Table A1, online only). Participants discussed current cancer care and were provided with an overview of cancer care delivery redesign options. All eligible patients and caregivers

spoke English; however, native languages included Spanish, Mandarin, and Hindi. The Stanford University Institutional Review Board approved the study.

Semistructured interviews were digitally recorded, transcribed, and imported into qualitative data management software (Atlas.ti, version 6.0; Scientific Software Development, Berlin, Germany). Two investigators (M.P. and D.M.) read the transcripts and created codes for key points within the text using an iterative process. Two trained coders independently coded the transcripts, discussed discrepancies, and modified the codebook with the principal investigator (M.P.). A Cohen's kappa using a randomly selected sample (33%) of quotes from each of the codes to measure consistency between coders was calculated, with scores ranging from 90% to 95%, suggesting excellent interrater reliability.²¹ Transcripts were thematically analyzed to identify 299 unique excerpts pertaining to care delivery. After ongoing and iterative analysis, consensus was reached among multiple investigators with respect to thematic saturation. Analysis was based on grounded theory (thematic analysis) and performed using the constant comparative method of qualitative analysis.^{22,23}

RESULTS

Interviews were conducted separately with 75 patients and 45 caregivers (Table 1). Domains and themes are discussed in the following paragraphs.

Domain 1: Cancer Care Deficiencies

Patients and caregivers articulated their desires to better understand the consequences of treatment choices on quality of life and prognosis (Table 2). Patients emphasized the importance of engaging family in their medical decision-making process while preserving their personal views. Specifically, some expressed difficulty in speaking truthfully with their doctors because their families had preestablished views of what the right decisions were. Others expressed that family support enhanced their ability to communicate openly with their clinical teams. Overall, patients and caregivers reported satisfaction with care but noted deficiencies with the way care was delivered. Major themes are identified as follows.

Theme 1: Poor patient-doctor communication within and outside of scheduled visits

Patients and caregivers expressed difficult communication with their doctors during and after clinic visits. One patient

Table 1. Participant Demographic Characteristics (n = 120)

Characteristic	No. (%)
Patients/families/caregivers	120 (100.0)
Families/caregivers	45 (37.5)
Patients	75 (62.5)
Diagnoses	
Hematologic malignancies	7 (5.8)
Breast	33 (27.5)
Lung	33 (27.5)
GI	31 (25.9)
Genitourinary	10 (8.3)
Head and neck	6 (5.0)
US location/region	
Northwest	32 (26.6)
Southwest	30 (25.0)
Midwest	18 (15.0)
Northeast	20 (16.7)
Southeast	20 (16.7)
Sex	
Men	70 (58.0)
Women	50 (42.0)
Race/ethnicity	
Hispanic	28 (23.3)
Non-Hispanic White	37 (31.0)
Non-Hispanic Black	26 (21.7)
Asian Pacific Islander	22 (18.2)
Other	7 (5.8)
Age	
18-30	18 (15.0)
31-50	27 (22.5)
51-70	33 (27.5)
> 70	42 (35.0)

stated that the volume of information provided in the first visit was a barrier to quality communication.

I heard the word cancer and it was Charlie Brown's teacher. I speak English but I wasn't hearing what the doctor said. There was so much information. There wasn't enough time to ask or would I even understand the answer to things that I really needed to ask. Later visits, even worse, because there was so much to talk about like my vomiting. It was hard to bring anything else up. You don't want a rushed answer about how long you are going to live.

Patients and caregivers also expressed concerns with interrupting a provider's day to obtain results for tests. One patient stated,

I never know what my labs are. I ask to see them but I don't want to hold the doctor. I don't wanna bother them.

A caregiver similarly stated,

We try to not call the office....Only when we need to...but we feel like we need to talk to someone but don't want to be those problem people who call all the time.

One patient reported,

I have a great relationship with my oncologist. She makes it easy to ask questions and spends as much time as needed with me. You have to wait an hour to see her but then she takes time to make sure all my questions are answered.

Theme 2: Perceived inadequate explanations of prognosis and challenges in initiating conversations around prognosis

Patients and caregivers repeatedly reported inadequate comprehension of their prognosis. One patient reported,

I want to ask, like, do I need to get my affairs in order. Am I going to die? You want the doc to bring it up almost so you don't have to. But when he don't, then, it's on us to ask and I don't know how to bring it up.

One caregiver stated,

We saw my mother suffer and wanted to stop treatment. We didn't want to upset the oncologist because he said "4 rounds of treatment" so we pushed her. It was hard to bring it up in a visit when she was already on schedule to get treated.

Another caregiver similarly reflected,

I see what treatments are doing to her [wife] and not sure she can take it even if it's helping the cancer but we don't know how to tell our doctors that or ask it. We think that if it wasn't working she would stop but we haven't had that conversation yet so we think it's working but don't know.

One caregiver had a dissenting view to this theme and stated,

My mom's doctor told us her prognosis on the first day. It was clear. We had somewhere between 4-6 months. We all remember it clearly because it was such a shock to hear. But, we knew she had limited time and it made it easier

Table 2. Sample of Quotes From Participants Regarding Cancer Care Delivery

<p>Theme 1: Poor patient-doctor communication within and outside of scheduled visits</p> <p>This theme was expressed in 92% of interviews with patients and 100% of interviews with caregivers.</p> <p>"My doctor sees patients once a week. They can get really backed up and if there is even a slight delay in the schedule, we are all delayed and so are our other appointments. There is really too little time to discuss all the things we want to and need to." (Patient)</p> <p>"The most 'normal' I feel is when I take a break from chemotherapy. That doesn't happen often. But I can't tell the doc that I need a break cause I don't wanna ruin the plan." (Patient)</p> <p>"I hate that I have so many problems always and they are different. Medicines help some but I also don't want to bother my doctor unless it's really bad and I need to, you know." (Patient)</p> <p>"My husband had uncontrollable pain, excruciating, really. I called the cancer center multiple times for over a week but no one ever returned our call. The operator said, 'I am calling you back to let you know that the nurse will call you soon.' But, I said, 'Every time I call I can't get in touch with anyone and my husband's symptoms worsen. Who do we call?' There was no really good answer. I ended up having to take him to the urgent care clinic and he got admitted which was really not what he wanted at all." (Caregiver)</p> <p>"My family speaks English but my father did not. There always is a problem with the translator phone so we have to translate the visit. I don't know many of the words and we don't know how to translate or whether father really understands what we are saying. Heck, I don't know if we understand what we are saying." (Caregiver)</p> <p>"I felt rushed through all the appointments. I spend over three hours waiting and all I get is a hurried visit where I feel like I am just another cancer patient. I don't relate to my doc at all. I don't expect that much anymore except having to wait a long time." (Patient)</p>
<p>Theme 2: Perceived inadequate explanation of prognosis and challenges in initiating conversations around prognosis</p> <p>This theme was expressed in 80% of interviews with patients and 95% of interviews with caregivers.</p> <p>"We feel helpless. Is there someone who can help to get through this? Too much to do all the time. We don't understand the words they use and who we can trust. We don't know how to ask any of the questions that we need to ask." (Caregiver)</p> <p>"My sister didn't know if it was okay to keep running. So she stopped. I asked the doctor but they didn't know. Sometimes she doesn't know how to bring up the little things or what to expect even when there are big things like if the treatment is working." (Caregiver)</p> <p>"My wife didn't want to let her doctor down by stopping chemotherapy early. She felt like she needed to go through with it so it took our family supporting her and being her advocate and voice. Not everyone has that." (Caregiver)</p> <p>"I didn't know how to bring up the important stuff, like, you know, how long do I have....My doctor didn't bring it up either so I never know if I have a long time or short time. I want to bring it up but don't know how." (Patient)</p> <p>"My mom was a Do Not Resuscitate/Do Not Intubate and was really clear that she didn't want any chemotherapy or other sort of treatments. It was a big decision on us but especially for my brother. At the end, he wanted her to receive everything...but it really took us having a family meeting to remember that it wasn't about us and her fear of dying and leaving us behind but about her and what she wanted. It was weird being in that role and not really knowing how do the right thing at the end." (Caregiver)</p>
<p>Theme 3: Lack of care coordination</p> <p>This theme was expressed in 100% of interviews with patients and caregivers.</p> <p>"When I was first diagnosed, I felt so lost. It was worse that the clinic told me to get laboratories and x-rays and then get my chemotherapy but I didn't even know where the places are in this clinic. I know they are so busy, so I didn't want to hold them up by asking stupid questions like about where things were. But it was scary because I felt like I was in another world and I didn't want to be late to my appointment but I really didn't know where I was supposed to be or when. It got better but then, now, that my treatments aren't really working, it feels like the same thing...that I am lost and no one is really helping to tell me where things are and I don't want to ask the stupid questions." (Patient)</p> <p>"We have no insurance. We couldn't pay for things like we didn't do the colonoscopy early and so now it is too late." (Caregiver)</p> <p>"We showed up the first clinic and they said that we needed to bring all of our records. Then we had to go around and get all of the records and bring them and then they told us they needed some tumor sample from the other hospital and we had to run around and get that too. It was really not okay and there was no one with a list to tell us what to do so that we didn't have to keep running around." (Caregiver)</p> <p>"The schedule was bad. I didn't know what to do. The doctor told me I needed to come for chemotherapy but then I had radiation too but my chemotherapy was so long that I missed the radiation. The same thing happened the next week. You would think the people making the appointments would know or that they talk to each other. It's the same clinic." (Patient)</p>

(continued on following page)

Table 2. Sample of Quotes From Participants Regarding Cancer Care Delivery (continued)**Theme 4: Inconvenient locations for care**

This theme was expressed in 60% of interviews with patients and 55% of interviews with caregivers and was specifically a concern among those who lived greater than 30 miles from oncology providers.

"I tried to call for my husband about his appointment and he had a lot of nausea. But, we knew that if we called they say go to emergency. He didn't want that so we stopped calling about these things." (Caregiver)

"It really takes a lot for me to go to clinic every two weeks. I like it because there are people I know there but it really is hard to get there with the traffic and I don't feel so good in the car." (Patient)

"The clinic is really far from my apartment. It is hard to get there and I need someone to drive me. I wanted to stay home a lot but I know that every Monday I am going to be at the cancer center all day." (Patient)

once we could talk about all that hard stuff that we had been avoiding.

Theme 3: Difficult coordination of various services needed for cancer care

Patients and caregivers expressed concern about coordination and reported consistent difficulty with scheduling appointments, obtaining health records, insurance authorization, and disability. One patient stated,

I don't know how to schedule my life much less radiation which is at one place and chemotherapy which is at another and labs yet another. I need to schedule rides to get to all these places and it feels like I am relying way too much on friends especially if I forget an appointment or if the appointment is cancelled.

Theme 4: Inconvenient locations for care

Patients and caregivers discussed difficulty traveling to appointments, especially when they experienced symptoms. One patient stated,

I am scared to walk the stairs outside of my apartment but I have to once a week. My family puts me in a chair and carries me out but I wish that there were some other way to get the chemotherapy. I ask to be at home as much as possible but they say it is hard to do this.

One caregiver stated,

These visits are in places that are far. The traffic is really hard because it can take up to an hour to get there. My mother is so nauseated and the car ride makes it worse plus when we get there we have to wait a long time which makes it even worse for her and for us.

One patient, however, did not mind the travel because of other aspects of the clinic:

I like seeing my new and old friends while I get my treatments. It makes me feel like I am not going through this alone and is a little nice to socialize every now and again.

Domain 2: Possible Solutions to Improve Cancer Care

Alternative providers: Nonmedical personnel as part of the care team could provide more patient-centered services, such as education, guidance, and general support, to patients and caregivers

Patients and caregivers emphasized that counseling, especially regarding diagnosis or treatment, could be improved by using, as adjuncts or replacements, nonmedical professionals (eg, peer support, community health workers; Table 3). Patients and caregivers expressed that alternative personnel could overcome some communication challenges expressed in Theme 1 by enhancing patient-provider communication outside of the clinic setting. Patients and caregivers thought that nonphysicians could build a relationship outside what traditional medical care provides. One patient said,

It's often my friends in the waiting room who are able to really listen, ask questions that make me think about things in a different way....They help me to think more about what I want for my life in a way that my nurses and doctors can't. Doctors and nurses and such are really good at knowing what medicine to give but the idea of bouncing my thoughts off others to think about being a person with cancer instead of a cancer patient is a good idea.

One caregiver expressed,

It helps to have someone that's not a doctor to talk about stuff with. My dad always said he would talk to someone

Table 3. Sample of Quotes From Participants Regarding Solutions for Care Delivery

<p>Alternative providers</p> <p>This solution was expressed in 100% of interviews with patients and caregivers.</p> <p>"I think it would be good to have someone to help me know better and someone like a person who can call me and explain could help me." (Patient)</p> <p>"If I had someone else to call, someone that wasn't as busy, it would be easier for me to call and ask all the questions I have." (Patient)</p> <p>"I needed someone to speak on my behalf, you know. I just felt like sometimes I wasn't being heard. I wanted a safe place with time to talk about these things like how I wanted to die but I also didn't want to complain cause I don't want to seem ungrateful for my care. So, yes, having someone like a nondoctor would help me to talk about these things without feeling rushed and in a safer place." (Patient)</p> <p>"I don't trust no one. I think, I am brown, that I get different respect. My neighbor had the same exact cancer and she got a different surgery and for some reason they tellin' me that I only need part of my breast taken out. My mama got cancer too and she died because she didn't have the money to come to a better place to get her medicines. I am in a better place but I have to make decisions for myself cause you don't know if you are getting bad advice. Someone who knows what I am going through could be good." (Patient)</p> <p>"It would have been great to have someone else to talk to like this nonphysician person who really gets it in a way that the clinic staff doesn't really. I think it would have helped for her, too, to have someone else to talk to and who could really ask the questions that we are avoiding and get her to talk about her wishes." (Caregiver)</p> <p>"I did okay with knowing I was dying. I am ready. I just need my husband to be okay with this. And, I didn't know how to break the news to my children and no one told me how to do this. It would help to have someone like a nondoctor person to help with this." (Patient)</p>	
<p>Home- and community-based locations</p> <p>This solution was expressed in 90% of interviews with patients and 95% of interviews with caregivers.</p> <p>"We all wanted some steps. My mother's clinic was far from her house and she can't walk down the stairs which makes it harder for her to get there. She also didn't know when her appointments were and it was hard to schedule one of us to take her to and from them. It would be better if we could get the visits closer to her home and I like the idea of inside the home." (Caregiver)</p> <p>"I told the doctor when they asked that I wanted to be at home. I didn't want the medicines if I had to come to the clinic. My daughter told me that I needed it so I did it but I wish that I could get them at home." (Patient)</p> <p>"I know I have a horrible disease but I want to know that I will do okay. That's why I look to talk to others in this waiting room. I have made a few bonds and we listen to each other here. The support piece is important and is why I go there. I don't think I would want it at home all the time." (Patient)</p> <p>"I don't know how you would do it, but if my dad could get treated at home or nearby, that would be the best solution. He hates going to the treatment center and really feels uncomfortable that other people that he knows will see him there. He's a private person so the home treatment is the best solution for him." (Caregiver)</p>	
<p>Alternative formats</p> <p>This solution was expressed in 100% of interviews with patients and caregivers.</p> <p>"Having a way to get the answers we need without going to the clinic would be great. Most of what we need is by phone anyways." (Caregiver)</p> <p>"Right now, most of what I do is call anyways. The problem is that the clinic doesn't return my call right away, so I usually end up waiting a long time for them to call back. If this were faster, I would use it all the time because it is better for me." (Patient)</p> <p>"My sister never wants me to call unless she thinks it is really an emergency but if this were set up to be appointments and more routine, I think she would use this a lot." (Caregiver)</p> <p>"I think the idea of using a telephone application would be a great way to get my mom's questions answered and her symptoms attended to." (Caregiver)</p>	

more like a person rather than a doctor because there's something different about talking to a friend who isn't a doctor. Then, that person can help to get my dad to think about how to bring stuff up that he may not bring up with the doctor.

Patients and caregivers expressed that alternative health personnel can improve perceived poor doctor-patient communication regarding prognosis and goals of care. One patient said,

This person will help focus more on things that are important to us as people not as patients. They have the time to really find out what fears we have and what is going on rather than rushing it in one visit.

Home- and community-based locations: In-home and community-based locations for care delivery would enhance patient convenience and reduce burden on caregivers and potentially improve quality of life for patients

Patients and caregivers strongly encouraged home-based services as a solution to current care delivery challenges. Some patients shared positive experiences with home visits and infusion centers in community-based locations. Although none had used a retail-based clinic for care, some had heard about them and thought they would be feasible and convenient. Some caregivers shared safety concerns. One stated,

In theory, it's nice. But, it would have to be safe and there needs to be a doctor close by in case something were to happen.

Alternative communication formats: Non-face-to-face formats for care would increase access, reduce burden, and potentially enhance quality of life for patients and caregivers

Patients and caregivers were enthusiastic about using non-face-to-face formats for care delivery as a solution to overcome the current care delivery challenges, specifically regarding poor communication and inconvenient locations of care delivery. Patients and caregivers shared positive experiences they had with telephone-based care, especially around symptom management.

You can do a lot more and allow more home time for us if there are other ways to talk to the doc and nurse instead of having to go to the clinic. I like the idea of having my symptoms taken care of by phone.

Other options included e-mail, text messaging, websites, and phone-based applications. Some patients used websites to obtain personalized information about their cancer and symptoms. One patient described communicating with her provider to discuss symptom management by e-mail:

I live a ways from the clinic and email my doctor about symptoms. It's a convenient way to get my needs met.

DISCUSSION

To our knowledge, ours is the first multisite qualitative study of patients with cancer and caregivers to better understand the current challenges they encounter and to identify patient-centered solutions that may benefit them the most. Study participants reported four primary gaps in cancer care delivery, including poor doctor-patient communication, insufficient attention to conversations about prognosis, lack of care coordination, and lack of access to care locations. Despite efforts to improve patient-provider communication regarding goals of care and symptom management,^{8,9,24-27} patients and caregivers noted persistent deficiencies,^{7,28,29} consistent with previous studies.^{2,5,10,11} Study participants identified three practical solutions to reduce these care gaps, including use of (1) nonphysician health personnel (eg, community health workers, patient navigators); (2) alternative care formats (eg, telephone-based care); and (3) extending community-based

care locations (eg, home visits, chemotherapy delivery). These themes and solutions map to the adapted Donabedian framework as detailed by Starfield³⁰ (Appendix Fig A1, online only). Each health system has a structure (or capacity), with characteristics that enable provision of care and influence processes (or performance) that lead to various aspects of health status. These components interact with, and are determined by, community resources, individual behavior, and the environment in which the health system exists.

Our findings reveal opportunities for improving cancer care from patient and caregiver perspectives and suggest that incorporating nonphysician health personnel into cancer care delivery is not only acceptable but also a patient-preferred solution. Although studies have examined the quality of care provided by lay health community workers in preventive cancer care delivery,^{31,32} no current studies have shown the benefit of these care providers in assisting with serious illness conversations or symptom assessment techniques. Research is needed to determine the effectiveness of these nonphysician personnel in these aspects of care delivery.

Care delivery in alternative formats was also an approach that was desired and used by some patients and caregivers. Patient and caregivers expressed a need for alternative communication options to enhance patient-provider communication (eg, e-mail, telephone, text messaging). Alternative payment models now financially support these previously unreimbursed alternative format approaches.^{17,33}

Patients and caregivers also strongly expressed cancer care delivery in alternative locations, specifically locations closer to homes and communities. However, these changes require a paradigm shift in current care delivery and a change in reimbursement. The redesign of organizations will need to support workforce, infrastructure, and technology to enable delivery of care in locations closer to and in patients' homes. Currently, retail clinics exist and are providing basic primary care functions.³⁴ With comprehensive oversight, these clinics could expand to provide cancer-related care, enhancing convenience and quality of life for patients who wish to remain close to home. The current reimbursement trend to reward value-based cancer care could also facilitate this goal.

Our findings must be interpreted in the context of our patient and caregiver population, representing a limited sample receiving care in US cancer clinics. However, our sample size for this qualitative study was large enough to reach saturation (the point when no new themes emerge from further interviews).^{35,36} In addition, we recruited participants from a

variety of geographic areas, including large cancer institutes and private-practice oncology clinics. We acknowledge, however, that these findings may not be generalizable to patients receiving care in other settings or outside of the United States. Furthermore, we focused on adult populations; therefore, our conclusions may not be applicable to pediatric populations. We also recruited only English-fluent participants. It is likely that replicating this study with patients and caregivers with limited English proficiency may identify other barriers to care. Finally, considerations of cost were not explored in this analysis.

To our knowledge, despite limitations, our findings represent the first study to assess patient and caregiver perspectives on current cancer care delivery and opportunities to inform cancer care redesign. As clinicians, researchers, and policy makers consider ways to radically transform our cancer care delivery system, the perspective of families and patients is critical to ensure the design of a system that meets the needs of these stakeholders. Among many populations, cancer care deficiencies are pervasive, and these gaps in care may be more pronounced for vulnerable patient populations. The patients and caregivers in our study provided details about their current experiences with cancer care inadequacies and supported opportunities to address these deficiencies through alternative providers, non-face-to-face formats, and alternative locations for care. These solutions should be evaluated for their effectiveness in future studies.

In conclusion, our findings are a rich reflection of patient and caregiver perspectives regarding current cancer care delivery and approaches to improve care delivery. The insights gained can lead to innovations in cancer care delivery that may achieve improved patient experiences and outcomes while placing attention on health care utilization. **JOP**

Acknowledgment

Supported by Department of Veterans Affairs Grant Nos. R25MD006857, IP1 HX001980-01, and U54MD010724 (V.S.P.). There was no external funding for the work submitted. The ideas and opinions expressed in this study are those of the authors.

Authors' Disclosures of Potential Conflicts of Interest

Disclosures provided by the authors are available with this article at jop.ascopubs.org.

Author Contributions

Conception and design: Manali I. Patel, Arnold Milstein

Collection and assembly of data: Manali I. Patel, Vyjayanthi S. Periyakoil, David Moore

Data analysis and interpretation: Manali I. Patel, Vyjayanthi S. Periyakoil, Douglas W. Blayney, David Moore, Andrea Nevedal, Steven Asch, Tumaini R. Coker

Manuscript writing: All authors

Final approval of manuscript: All authors

Accountable for all aspects of the work: All authors

Corresponding author: Manali I. Patel, MD, MPH, 875 Blake Wilbur Dr, Stanford, CA 94305; e-mail: manalip@stanford.edu.

References

1. Siegel, RL, Miller, KD, and Jemal, A: Cancer Statistics, 2017. CA: A Cancer J for Clin, doi:[10.3322/caac.21387](https://doi.org/10.3322/caac.21387)
2. Hagerty RG, Butow PN, Ellis PM, et al: Communicating with realism and hope: Incurable cancer patients' views on the disclosure of prognosis. J Clin Oncol 23:1278-1288, 2005 [Erratum: J Clin Oncol 23:1278-1288, 2005]
3. Mack JW, Weeks JC, Wright AA, et al: End-of-life discussions, goal attainment, and distress at the end of life: Predictors and outcomes of receipt of care consistent with preferences. J Clin Oncol 28:1203-1208, 2010
4. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. JAMA 274:1591-1598, 1995 [Erratum: JAMA 275:1232, 1996]
5. Butow PN, Dowsett S, Hagerty R, et al: Communicating prognosis to patients with metastatic disease: What do they really want to know? Support Care Cancer 10:161-168, 2002
6. Weeks JC, Cook EF, O'Day SJ, et al: Relationship between cancer patients' predictions of prognosis and their treatment preferences. JAMA 279:1709-1714, 1998
7. Fisch MJ, Lee JW, Weiss M, et al: Prospective, observational study of pain and analgesic prescribing in medical oncology outpatients with breast, colorectal, lung, or prostate cancer. J Clin Oncol 30:1980-1988, 2012
8. Fortner BV, Okon TA, Portenoy RK: A survey of pain-related hospitalizations, emergency department visits, and physician office visits reported by cancer patients with and without history of breakthrough pain. J Pain 3:38-44, 2002
9. Mayer DK, Travers D, Wyss A, et al: Why do patients with cancer visit emergency departments? Results of a 2008 population study in North Carolina. J Clin Oncol 29:2683-2688, 2011
10. Barg FK, Cronholm PF, Straton JB, et al: Unmet psychosocial needs of Pennsylvanians with cancer: 1986-2005. Cancer 110:631-639, 2007
11. Earle CC, Neville BA, Landrum MB, et al: Trends in the aggressiveness of cancer care near the end of life. J Clin Oncol 22:315-321, 2004
12. Smith AK, McCarthy EP, Paulk E, et al: Racial and ethnic differences in advance care planning among patients with cancer: Impact of terminal illness acknowledgment, religiousness, and treatment preferences. J Clin Oncol 26:4131-4137, 2008
13. Degenholtz HB, Arnold RA, Meisel A, et al: Persistence of racial disparities in advance care plan documents among nursing home residents. J Am Geriatr Soc 50:378-381, 2002
14. Periyakoil VS, Neri E, Kraemer H: Patient-reported barriers to high-quality, end-of-life care: A multiethnic, multilingual, mixed-methods study. J Palliat Med 19:373-379, 2016
15. Page RD, Newcomer LN, Sprandio JD, et al: The patient-centered medical home in oncology: From concept to reality. Am Soc Clin Oncol Educ Book e82-e89, 2015
16. Sprandio JD: Oncology patient-centered medical home. Am J Manag Care 18:SP191-SP192, 2012
17. Centers for Medicare and Medicaid Services: Oncology Care Model. <https://innovation.cms.gov/initiatives/oncology-care/>
18. Kline RM, Bazell C, Smith E, et al: Centers for Medicare and Medicaid Services: Using an episode-based payment model to improve oncology care. J Oncol Pract 11:114-116, 2015
19. Patel MI, Moore D, Milstein A: Redesigning advanced cancer care delivery: Three ways to create higher value cancer care. J Oncol Pract 11:280-284, 2015
20. Donabedian A: The quality of care. How can it be assessed? JAMA 260:1743-1748, 1988
21. Landis JR, Koch GG: The measurement of observer agreement for categorical data. Biometrics 33:159-174, 1977

22. Glaser B, Strauss A: *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, IL, Aldine Publishing Company, 1967
23. Braun V, Clarke V: What can "thematic analysis" offer health and wellbeing researchers? *Int J Qual Stud Health Well-being* 9:26152, 2014
24. Temel JS, Greer JA, Muzikansky A, et al: Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 363:733-742, 2010
25. McKenzie H, Hayes L, White K, et al: Chemotherapy outpatients' unplanned presentations to hospital: A retrospective study. *Support Care Cancer* 19:963-969, 2011
26. Caraceni A, Martini C, Zecca E, et al: Breakthrough pain characteristics and syndromes in patients with cancer pain. An international survey. *Palliat Med* 18: 177-183, 2004
27. Dodd MJ, Dibble SL TM, Thomas ML: Outpatient chemotherapy: Patients' and family members' concerns and coping strategies. *Public Health Nurs* 9:37-44, 1992
28. Janda M, Eakin EG, Bailey L, et al: Supportive care needs of people with brain tumours and their carers. *Support Care Cancer* 14:1094-1103, 2006
29. Gustafson DH, Taylor JO, Thompson S, et al: Assessing the needs of breast cancer patients and their families. *Qual Manag Health Care* 2:6-17, 1993
30. Starfield B: *Primary Care: Balancing Health Needs, Services, and Technology*. New York, NY, Oxford University Press 1998
31. Wells KJ, Luque JS, Miladinovic B, et al: Do community health worker interventions improve rates of screening mammography in the United States? A systematic review. *Cancer Epidemiol Biomarkers Prev* 20:1580-1598, 2011
32. Brownstein JN, Cheal N, Ackermann SP, et al: Breast and cervical cancer screening in minority populations: A model for using lay health educators. *J Cancer Educ* 7:321-326, 1992
33. Centers for Medicare and Medicaid Services: Quality Payment Program. <https://qpp.cms.gov>
34. Mehrotra A, Wang MC, Lave JR, et al: Retail clinics, primary care physicians, and emergency departments: A comparison of patients' visits. *Health Aff (Millwood)* 27: 1272-1282, 2008
35. Green J, Thorogood N: *Qualitative Methods for Health Research* (ed 2). Thousand Oaks, CA, Sage, 2009
36. Guest GB, Bunce A, Johnson L: How many interviews are enough? An experiment with data saturation and variability. *Field Methods* 18:59-82, 2006

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**Redesigning Cancer Care Delivery: Views From Patients and Caregivers**

The following represents disclosure information provided by authors of this manuscript. All relationships are considered compensated. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the subject matter of this manuscript. For more information about ASCO's conflict of interest policy, please refer to www.asco.org/rwc or ascopubs.org/journal/jop/site/misc/ifc.xhtml.

Manali I. Patel

Consulting or Advisory Role: Castlight Health, Celgene

Vyjeyanthi S. Periyakoil

No relationship to disclose

Douglas W. Blayney

Consulting or Advisory Role: Clinical Oncology Advisory Group, Physician Resource Management, Bristol-Myers Squibb, Carevive Systems, Oncothyreon, Varian Medical Systems

Research Funding: Amgen, BeyondSpring Pharmaceuticals

David Moore

No relationship to disclose

Andrea Nevedal

No relationship to disclose

Steven Asch

No relationship to disclose

Arnold Milstein

Honoraria: Davita Rx, Frazier Healthcare Partners

Consulting or Advisory Role: Amino Advisory Board, LandmarkHealth

Research Funding: Evolent Health

Patents, Royalties, Other Intellectual Property: Over-the-counter medication (Inst)

Tumaini R. Coker

No relationship to disclose

Appendix

Table A1. Sample of Interview Questions

Cancer care delivery

- Will you please describe your (or your loved one's) background and current medical needs?
- How did you become involved with this clinic?
- Did you see a need for improvements to current care? Why or why not?
- What kind of services were you getting from the clinic?
- What kind of services were you getting to help you?
- Will you please describe your experiences with cancer to the best of your recollection? If you can, please tell me about the major milestones and the month and year in which they each occurred.
- Which type of communication has tended to be most helpful for you?
- Can you describe how you made decisions about your cancer care?
- Can you describe your experiences and the type and level of support you had during your care?
- What kind of external support did you receive from the care team?
- How did the care team influence your confidence to discuss goals for treatment and your life?
- Do you feel like you were able to get all the care you would have liked? Why or why not? Is this true for the other patients or caregivers? Why or why not?
- How would you improve current care delivery? Why?

Potential solutions

- On a scale of 0-10, how successful do you think a non-health care provider would be?
- On a scale of 0-10, how successful would nontraditional formats for discussing health issues with your team be?
- On a scale of 0-10, how successful would locations of care closer to home be?
- How would you imagine that these solutions could improve current care delivery? Why? How would you imagine that these solutions could hinder current care delivery? Why?

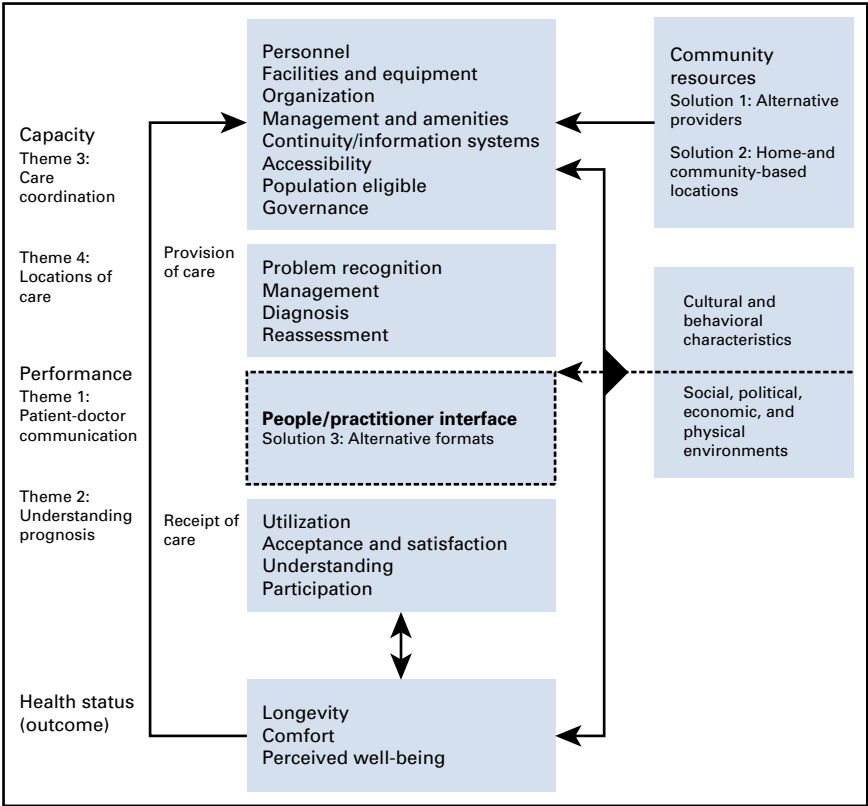


Fig A1. Conceptual model of redesigning cancer care delivery themes and solutions. Adapted from Starfield.³⁰