

Research Article

A Cancer Patient Journey: 360 Degree Review during Acute Treatment Phase

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2019; **Published:** February 11, 2019**Abstract**

Cancer is a chronic illness with acute episodes lasting for years. Most cancer patients have coexisting comorbidities, which affect cancer treatment outcomes and make a shared care model for chronic diseases essential. There is a considerable gap between the achievable and delivered quality of care for cancer patients. We used a case study approach to examine the complexity of cancer management, from the perspective of one person's case as interpreted by the care team. It allowed the complexity of cancer management to retain its holistic and meaningful characteristics. We interviewed the patient, caregiver, Primary Care Physician (PCP), oncologist and oncology nurse. Interviews were audio recorded and analyzed with ATLA Sti, qualitative statistical software. Participants also completed a basic demographic survey. Common themes were identified, analyzed and discussed. Results identify three main themes: lack of longitudinal relationship with PCP, communication barriers, and ambiguous health care provider roles. Communication barriers can be associated with the other two main themes. Our results show that shared care for cancer management is lacking during the acute cancer treatment phase. Communication barriers between the PCP and oncologist along with lack of continuity of care and unclear role of the PCP are major contributors for fragmented cancer care.

Keywords: Cancer; Shared care; Health care delivery; Chronic care model; Qualitative; Communication barriers

Abbreviations

CCM: Chronic Care Model; PCP: Primary Care Physician; ER: Emergency Room; CDC: Center for Disease Control and Prevention; EHR: Electronic Health Record; HIE: Health Information Exchange

Introduction

Cancer is a leading cause of morbidity and mortality worldwide. In 2013, there were approximately 1,660,290 new cancer cases and 580,350 cancer deaths in the US [1]. According to the Center for Disease Control and Prevention (CDC), cancer is classified as a chronic disease and described as of long duration and generally slow progression and the acute treatment phase of cancer patients requiring chemotherapy and radiation, last weeks, months or years. Studies have shown that cancer patients receive fragmented care especially during the acute treatment phase [2-5] stemming from system problems such as lack of health insurance, communication problems between healthcare team members, [3,6] and lack of role clarity among team members [7-10].

The purpose of this study was to gather a qualitative description of collaborative care by interviewing cancer patients, their caregivers, Primary Care Physicians (PCP), Oncologists and Oncology nurses to better understand cancer patients' initial journey in the healthcare system.

Methods

A case study approach was used for this research to examine

the complexity of cancer management from the perspective of one person's case as interpreted by multiple people. It allows the complexity of cancer management to retain its holistic and meaningful characteristics while being studied [11]. The study is guided by the Chronic Care model (CCM) a proactive approach to keep patients healthy through productive collaboration between community and health systems; therefore the study generalizes to the theoretical propositions of the chronic care model and not the population [12]. This model identifies six structural elements that encourage high-quality chronic disease management: the community, the health system, self-management support, delivery system design, decision support and clinical information systems. We applied a comprehensive approach to the case study method including theory driven design; data collection through interviews focusing on multiple perspectives; and data analysis using a triangulation method that incorporates all perspectives into one case study database (hermeneutic unit) for review.

Case studies are best suited to answer how and why questions [13], such as how does a patient experience the initial diagnosis and management of cancer from a holistic perspective? Interviews from six participants (patient, caregiver, PCP, oncologist, oncology nurse, and coordinator), associated with one case represented multiple perspectives of the same interested topic, therefore achieving data triangulation [13].

The study utilized a purposeful sampling method [14,15]. The sample was taken from a larger university healthcare system, a

predominantly safety-net facility serving uninsured, undocumented and low-income patients. PCP identified new cancer patient (<3 months with diagnosis) and referred the patient to the study. The patient then identified her caregiver, oncologist, oncology nurse, and clinic coordinator.

The interview guide was developed based on the six key areas of the CCM. It is theorized that focusing on these elements should foster productive interactions between patients who take an active role in their care and informed clinicians who are supported by adequate resources and expertise [16,17]. Development of the interview guide was an iterative process in which researchers developed and discussed questions, which contextualized the CCM within cancer management.

Once questions were approved, they became part of the official interview guide, which was reevaluated for consistency and changed if researchers felt that questions were being misinterpreted. Main questions included: Tell me the story of how you learned you had cancer? Who did you talk to about your cancer diagnosis? How do your PCP and Oncologist work together to manage your cancer and general medical care? The researcher conducting the interviews was specifically chosen because she was not a healthcare practitioner but is knowledgeable in social science research of chronic conditions. Her inexperience served as strength to the study because she was not able to create leading questions or force participants into expected outcomes.

Data collection consisted of semi-structured interviews with all participants. The approach of starting with the patient and then interviewing the caregiver and the clinicians helped to understand how the same events were viewed from different perspectives. Interviews were about one hour long, focused on cancer management. Each interview was recorded and transcribed for analysis by AtlasTi. Participants also completed a basic demographic survey that captured gender, age, ethnicity, marital status, income, education, health insurance, and diagnosed conditions. All research activities were reviewed and approved by the University of Texas Health Science Center San Antonio Office of Institutional Review Board.

Results

Our sample included interviews with 1 cancer patient and her caregiver, PCP, oncologist, oncology nurse and care coordinator. Specific ages of subjects, years of practice, and specialties were captured see Table 1,2.

The results identify a major breakdown in the delivery system design highlighted in the CCM. Rather than emphasizing proactive systems that follow up on general health or assign case management for high risk potential cancer patients, the current approach to cancer treatment and management is reactive in nature. The three main themes, which are organized around the patient's experience through the health care system- from cancer diagnosis to treatment, are:

Lack of longitudinal relationship with PCP

This theme supports a known system problem in which people who are the sickest and need health insurance the most do not have it. Therefore, these patients do not have a relationship with a PCP. In this case study, the patient did not have an established PCP due to loss

of insurance, secondary to unemployment:

Patient: "At that time I did not [have a primary care physician]... I was one of those persons that go from payday to payday and I could not afford health insurance... I had it one time at a job...but I started getting very sick... I had severe high blood pressure and I had to quit... At that time, I realized that I did not even think about my health insurance... So, when I went into the emergency room, I did not have a doctor. I didn't have a regular doctor. I was not registered with the [local county assistance health program]..."

The patient ended up in the emergency room for severe chest pain and was diagnosed as having Leukemia. Patient was told about diagnosis and sent to oncologist to start chemotherapy.

Patient: "I remember before I got released, my cell count was so high, and they needed to bring it down...I did not know nothing about that. I was learning that my white blood cells were cancerous..."

The first PCP visit was four months after her leukemia diagnosis and after receiving three cycles of chemotherapy.

Patient: "After my fourth visit to the [cancer treatment center] they told me that I need to call the [healthcare system] and I needed to get a primary care doctor. So that was about four months later and that is when I first signed up to get my primary care doctor."

The patient was assigned a new PCP in a teaching facility, consisting of residents and faculty members divided into teams. Every visit a different provider saw the patient.

Patient: "Usually I see a different [provider], it is like a set of doctors that all work together. So I can't say it is one doctor..."

This lack of a longitudinal relationship with a PCP appeared normal to the patient; therefore, she began to rely heavily on the oncology team for things that a PCP could manage.

Communication barriers

The communication barriers surrounding cancer treatment began between the patient, caregiver and healthcare providers almost immediately. As the patient was diagnosed with cancer in the ER, she felt she was not able to get answers for her questions,

Patient: "The whole time all I was thinking, I have cancer. I have cancer! What is Leukemia... am I going to die... I heard them talking between themselves that it might be Leukemia... I asked is it ok doctor, what do you think it is? [And] they didn't want to give me the exact diagnosis yet." Similarly, the caregiver was also not able to communicate and get all her questions answered:

Caregiver: "I feel like the only time I talked to anybody was that day...a lot of questions I had, I just used my own resources... [The providers asked]-If you have questions... and then they gave us some packets and pamphlets. I relied mostly on my mom for communication... there's that communication barrier. My mom has a high school education, GED, and she doesn't understand lots of words."

The caregiver's impression was that due to patient's privacy, physicians were not supposed to communicate with her.

Caregiver: "I always assume, it's a privacy thing... I just wish there

Table 1: Demographics of Patient and Caregiver.

Role	Sex	Age	Ethnicity	Cancer	Insurance	Marital Status	Education	Monthly Income
Patient	F	63	Hispanic	Leukemia	County System	Divorced	GED	Less than \$1,000
Caregiver	F	31	Hispanic	n/a	Private	Married	College Graduate	\$2,500- 3,500

Table 2: Demographics of Providers in Case Study.

Role	Sex	Ethnicity	Specialty	Years of Experience
PCP	F	White	Family Medicine	25
Oncologist	M	Asian	Hematology	29
Nurse	F	Hispanic	Hematology	
Coordinator	F	Hispanic	Family Coordinator	12

was a mean for me to communicate directly with them (physicians) or staff or nurse.”

When asked if she had been included in any initial discussion about cancer or leukemia,

Caregiver: “no”. After a few months, the oncologist provided a video for her to share with her family members. The caregiver also shared that the practice setting prevented her from communicating with the healthcare team,

Caregiver: “I feel like there’s a resident that come in as a group with the doctors and learn, so I feel like I didn’t want to interrupt their learning with questions.” Additionally, the caregiver identified lack of communication between the PCP and oncologist as a barrier for effective collaboration.

Caregiver: “I feel like there’s a lack of communication between them. That’s a prescription given to her by her cancer doctor. Then the PCP will say, That’s not working out for you, let’s take them off, so that makes me uncomfortable, just in the sense that I feel like you should ask [the oncologist] first... My mom’s been bounced back and forth between vitamins and medications that she’ll get prescribed by one doctor, and then another doctor will change their mind. That makes me uncomfortable. I feel like there’s a lack of communication between them.”

There was no arranged method of communication between the patient, PCP and oncologist, therefore the patient could not communicate acute problems like side effects of medications, common cold, nausea, vomiting or minor symptoms. Rather, when the caregiver called to report a concern of patient’s excessive vomiting, she was told by the appointment clerk to go to the ER. At times, the ability to provide advice was contingent on the flow of clinic traffic, phone bank person and on call nurse knowledge. Patient called oncologist office and got same advice to go to ER.

Both the PCP and oncologist identified lack of communication as a barrier in the development of a collaborative model for patient management. The distance between locations and time constraints of both PCP and oncologists, and the different Electronic Healthcare Record systems. Made it difficult to communicate.

The physical distance between facilities was a physical difficulty but also a relational issue.

Oncologist: “The physical issue of being based in a downtown

[building] and having oncology services out at medical center [approximately 12 miles away]. You can’t pop over at lunch for a meeting ever, I suppose. I think the location of the [cancer treatment center] is not convenient for the vast majority of the patients we see down here. That’s for sure.”

PCPs do not have time to serve on cancer boards, even if invited, and oncologists do not communicate with PCP by phone due to time constraints or follow up letters about their patients.

Oncologist: “No one’s going to serve on a board if they’re all in clinic full time, of course. Everyone is busy so the communication is lacking... because we in oncology have been very short staffed.”

The lack of communication was further promoted because the cancer treatment center and the patient’s PCP clinic had different Electronic Health Record (EHR) systems.

Oncologist: “It is not possible for providers to look into each other notes and management plan. You’ve got the problem of the two computer systems that don’t talk to each other so they don’t see what they are doing in [the EHR] and we don’t see what they are doing in their EHR, so that makes it very difficult just all around.”

No follow-up letter was sent between providers and no point of contact within the PCP and oncology clinic was assigned communication continued to fail. The PCP was expected to communicate through the oncology on call resident or the general front desk person for oncology if a particular concern or question had to be addressed. This form of communication resulted in duplicate lab tests and confusion about patient’s treatment, but most notably relied on the patient as the main communicator between the PCP and oncologist. The PCP, oncologist, and coordinator realized that the break in communication made it more difficult for all involved and resulted in unnecessary delays,

PCP: “These are all unnecessary barriers in communication between the two offices and one of them is the fact that you can’t just book the patient before the patient leaves. sometimes you think you are conveying information, sometimes they don’t receive it.”

Ambiguous health care provider role

The patient, caregiver and healthcare providers agree that the PCP should be an essential part of the management team; however, all ambiguously understands the role. The PCP was viewed as important for the emotional support of the patient and family,

Patient: “She [the PCP] asked me if I ever got depressed. I told her no, I am okay. She said, it is okay to say it if you are. She tells me, it doesn’t take from you. I remember those words, it doesn’t take from you. When she said that, I knew what she was talking about and I told her; when I get in the shower sometimes I just breakout crying...She says, good... let it out...it is okay to feel that way. I would feel that way too.”

However, the PCP was not comfortable in managing specific

chemotherapy related side effects. The PCP felt that their strengths were to manage chronic conditions,

PCP: “we’re so narrow minded and struggling with cancer diagnosis...looking after hypertension, diabetes, hyperlipidemia, etc. etc.” Health management issues like depression, existing chronic conditions like hypertension or diabetes were a common occurrence in primary medicine, which complemented oncologists’ limitation. The oncologist felt that in their pursuit of cancer specialty, they should be able to rely on the PCP for support of common chronic disease management,

Oncologist: “Honestly my knowledge of ideal hypertension management has declined... even though I am an internist at heart... I quickly need primary care support to manage hypertension, as well as routine health maintenance of immunizations and recommended cancer screenings.” It is agreed that PCP has an important role in the management of new cancer onset or the worsening of conditions like diabetes, hyperlipidemia, thyroid problems or osteoporosis resulting from chemotherapy side effects.

Oncologist: “We [the oncologist] make the diabetes worse, so we constantly want to work with primary care teams.” The oncologist identified that the PCP should be seen as,

Oncologist: “An educator or tie-breaker in terms of treatment decision making.”

Discussion and Conclusion

This study reflects a typical journey of an underprivileged, uninsured cancer patient as she makes her way through the American healthcare system and identifies the serious gaps and areas of improvement for cancer patients who are most in need. It is unique in that data is collected and interpreted from the patients’ perspective and captures all perspectives on the experience. No similar studies were found in the current literature. It most notably shows the absence of PCP in the treatment and management of seriously ill cancer patient. This particular patient lost her health insurance due to uncontrolled hypertension resulting in the loss of employment. This resulted in a delay of cancer diagnosis as the patient kept on postponing and neglecting the symptoms as long as she could tolerate. She was diagnosed as having Leukemia in the emergency room after a twelve-hour wait.

Our findings confirm that the PCP is not an active member of patients’ management team while they are undergoing acute cancer treatment like chemotherapy [18-20]. Main barriers identified are the same as others identified in earlier studies. Similarities included a lack of longitudinal relationships with the PCP, communication issues between patient, caregiver, PCP and other healthcare team members, and a lack of role clarification for PCP and oncologist [10, 20-23]. An exception to these barriers is the patient and caregiver’s inability to communicate with PCP due to the teaching practice setting.

Not having a PCP at the time of cancer diagnosis was evident in our study; the first PCP visit took place after the fourth chemotherapy visit, which was approximately 3½ months into treatment. This is a common observation due to a large number of uninsured sick patients. Studies have shown that 1 in 5 Americans reported not getting or delaying medical care, and the percentage of uninsured

patients 45 to 64 years of age increased from 13.1% to 15.6% [24,25]. Additionally, the patient did not have access to a PCP after obtaining healthcare insurance due to the PCP’s busy schedule and the absence of special arrangements for cancer patients or the availability of same day appointments, which resulted in patients ER visits. The use of ER as a mechanism to receive primary care services is a serious and growing problem in the US, due to increased demand of primary care services [26]. Previous studies have also shown that there is an increased use of healthcare services by cancer patients when they are undergoing acute cancer treatment by chemotherapy and radiation as well as following treatment [27,28]. Ideally, there should be special provisions or the identification of a key contact person for cancer patients in PCP offices.

Lack of communication was the most prominent problem identified by the patient, caregiver and healthcare team. The main communication failure identified was between the PCP and the oncology team, confirming similar findings identified in other studies [29-33]. The federal government has offered incentives for meaningful use of information technology as a key tool for improving care coordination, which resulted in an increased use of EHR by physicians and hospitals [34,35]. In our study, the use of different EHRs by the oncology team and the PCP office was problematic. The PCP could not access patient information from the oncology visit and there was no formal follow up letter from oncology. Therefore, the PCP did not have any idea about chemotherapy regime or patient’s prognosis. Specifically, the breakdown in communication resulted in confusion about medications. Similarly, the patient and caregiver expressed frustration about the lack of communication because it placed a larger burden on the patient. The patient became the main communicator between oncologist and PCP, which is not an acceptable practice.

Not knowing the point of contact in the PCP and oncology office was an additional reason identified by PCP and oncologist for communication breakdown. Good care coordination, for safe and appropriate management of chronic conditions like cancer are essential. However care coordination remains inadequate and a major cause of healthcare expenditure and mistakes [36,37]. Possible solutions include uniform access to EHRs, clear identification of the patient’s PCP and oncologist, identification of point of contact in each office, and a structured follow up letter from oncologist to PCP [38]. Additionally, incorporating more Health Information Exchange tools within EHRs can improve care [29-31,33]. Further studies are needed to evaluate the efficacy of these measures. Ideally, health information technology systems should account for human factors both tolerating human limitations and augmenting human strengths [39].

Time constraint was an additional reason identified by the PCP and oncologist for the communication breakdown. There is no formal reimbursement for physician or staff time used for communication and coordination between providers by insurance companies [40]. Additionally, the shortage of PCPs and oncologists, and increased number of cancer patients makes care coordination more difficult [41]. A system wide change is needed in order to address these issues and acknowledge that time reimbursement will produce real improvement in patient care and reduce healthcare cost. The patient and caregiver identified the teaching hospital setting as an inhibitory factor because they felt that asking questions and communicating

with healthcare providers would interfere with learning. The awareness of patient and care giver in the learning process of students and residents is a new finding by this study. It requires that teaching physicians take extra steps to include the patient and care giver in their discussions and make them feel like part of the team. Another option can be to formally include the patient in discussions rather than to discuss the patient as an object of learning during rounds or completing management discussions without the patient.

Lack of PCP role clarification was another barrier identified for effective collaboration [42-44]. The current norm accepts that PCPs will not be a part of the cancer patient healthcare team, so the patient and caregiver were not clear about the PCP role; their expectation was that the PCP would serve as emotional support and manage routine health maintenance such as immunizations.

Studies have shown that PCPs can play an important role in the management of patients with cancers and coexisting chronic conditions, common side effects of chemotherapy, common acute conditions like viral illnesses and helping patient to make informed decisions about management, or end of life issues [45] etc. In this case study, the oncologist agreed that the PCP was an important part of the healthcare team, and the PCP was comfortable in fulfilling all these roles. Clear role assignment of healthcare team members will decrease the role confusion and potentially impact patients' unnecessary ER visits, reducing patient discomfort, patient's and healthcare cost.

In summary, our study revealed many barriers for collaboration during the initial cancer treatment phase, most notably between the PCP and oncologist. Our findings highlight that the lack of insurance for people needing it most results in delaying diagnosis and increased ER workload. Even though there is an abundance of resources and expertise available, the lack of collaboration and fragmented effort results in a wide gap between possible and actual care delivery for sick patients in general, but cancer patients specifically. The lack communication identified as main barrier by this study forces patients to become the main communicators between healthcare teams.

The major weaknesses of this study are that it was conducted in a big teaching hospital setting and it describes the experience of only one patient. However, the purpose of a case study is to examine the complexity of a phenomenon (cancer management) while it retains its holistic and meaningful characteristics. Similarly, the major strength of this study is that it investigates an underserved uninsured patient from their perspective. The study describes the complete experience, as it has been understood by the patient, caregiver, and patient healthcare team.

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