



Understanding the Illness Experiences and Barriers to Treatment of Cancer Patients





Our Agenda

- Provide a background of Mixed Methods Research and Major themes of our work
- Discuss process of synthesizing patient data and feedback
- Propose Interventions and next steps





1

Background

Generating a background section from previously synthesized data



Lab Goals

- ◇ Identifying Disparities in Palliative care amongst cancer patients
- ◇ Past papers analyze:
 - The perception of breast cancer survivors
 - The relationship between spirituality and QOL for black cancer patients experiencing pain
 - The gaps existent in pain management guidelines



**PALLIATIVE
CARE**



Study Aims

- ◇ Analyze patient interviews to understand:
 - Illness Experience
 - Pain Management Experience
- ◇ Develop major themes or areas of concern voiced by patients
- ◇ Gain a perspective on disparities in patient experiences

Interview patients
During this stage responses are collected from patients recounting their experiences



Pose Interventions and Re-evaluate
During this stage we pose appropriate interventions based on our analysis, and potentially implement these improvements and re-evaluate

Categorize and Analyze Feedback
During this stage we identify particular patterns found in patient feedback and highlight gaps apparent in existing programming





Major Themes: Cancer Patient Illness Experiences

- ◇ Care Coordination
- ◇ Supportive Care Programs
- ◇ Issues of Social Isolation
- ◇ Travel and Transportation
- ◇ Financial Toxicity
- ◇ Community Resources





Mixed Methods Research

- ◇ Often used when project is multifaceted, with many phases
- ◇ Uses both quantitative and qualitative data
- ◇ Quantitative
 - Deductive, hypothesis testing, random sampling, statistical analysis of numeric data
- ◇ Qualitative
 - Inductive hypothesis generating purposeful sampling, iterative interpretation of data





Our Study Design

- ◇ Exploratory Sequential Design
- ◇ Qualitative Data collection and analysis first
- ◇ Qualitative results form foundation for quantitative phase
- ◇ Interviews conducted with over 30 people consisting of cancer patients and their families and over 800 unique interview responses





2

Data Synthesis

Stratifying Patient Feedback



Important Tools

- ◇ Atlas
- ◇ Literature Review
- ◇ Compiling Resources
- ◇ Interpreting Qualitative Data
- ◇ Synthesizing Data



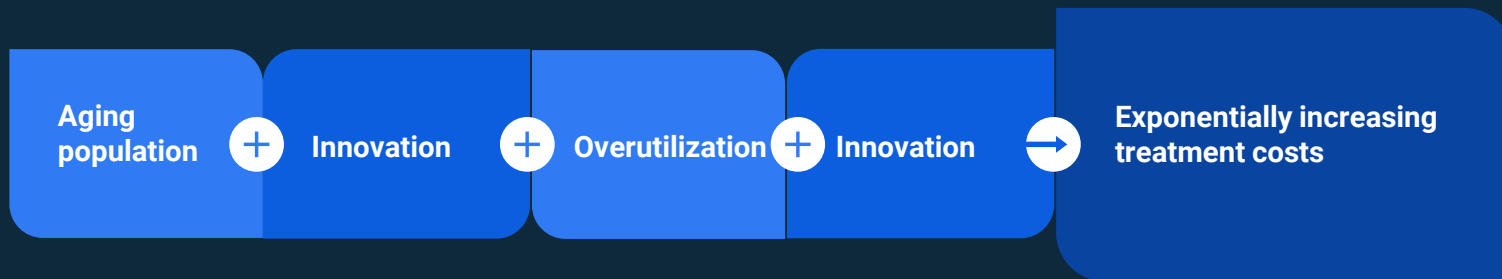


\$ 125 Billion

Current expenditures related to cancer in 2010

\$173 Billion

Expected expenditures by 2020





Financial Toxicity

- ◇ Financial toxicity related to out of pocket expense
- ◇ Rising costs of cancer care during this decade.¹
 - 9.7% chronic condition patients vs 13% of cancer patients report high objective financial burden²
- ◇ Care quality and well being affected by financial distress
 - Some patients decide against treatment because of cost³
 - Higher costs result in prescription abandonment and nonadherence^{4,5}





'Financially, and right now, I'm knocking on wood. We're doing okay. We were a little put back that when he first had surgery ten years ago and he was out for that. Then, he went back to work.

He felt like he wasn't producing the way he should, so he asked for longer time. The end result was that they let him go with no severance pay, nothing. He went out on disability, and that was it. I think, if anything, that was just a shock to him. Where all the years, work took priority and that was their thank you to him.

White Patients

1

'I had just started the job and I had to [inaudible 03:28] my cancer sessions. I wasn't there that long and wasn't eligible for disability so I had to resign.

2

'Well the first cost I think...the huge cost was the wig was \$600 and that's just crazy. It was, you know, I went to a local place because you just don't want to just walk around without your hair. That was expensive. And then of course the cost of going into the city and parking. At the [health system 2 chemo building] they do take care of your parking when you have chemo but there is cost all related to that. That's... I wish I was spending it on a vacation.

African American Patients

'Finances, of course, is important, it's an ongoing issues, trying to keep on top of keeping the bills paid, and making sure things are taken care of. That it was difficult with energy levels being low, very low, so I didn't do a lot, so things in my house got neglected, but it was okay

'The financial part was hard because the prices that they charge for this stuff is outrageous. I mean it's just...my bills for one month were like \$17,000



Possible Intervention Areas

Cost Conscious Training

Hospitals can invest in training their physicians to become more cost conscious in choosing their procedures and making clinical decisions.

Streamlining Prescribing Providers

From an administrative standpoint, reducing the amount of providers who are prescribing medications to patients.

Patient and Social Worker Pairings


Pairing patients and their family members with a social worker or financial counselor at the time of their diagnosis



Insurance Issues

- ◇ Navigating insurance information was a recurring obstacle for patients
- ◇ High deductibles, high copay leading to high out of pocket costs
- ◇ High costs for resources such as support groups
- ◇ Patients were unsure about what they were paying for and what insurance covered





'Well, here's a situation that happened. Dr. [name] is the world's expert on the type of cancer I have. A year ago—year, year-and-a-half ago—he decided that he was gonna give me a prophylactic treatment of a mild chemo. He starts, and lo and behold if the insurance company doesn't say, "It's not covered. You don't have any evidence of disease. We're not paying for this."

For whatever reason, Dr. [name]'s office put through an appeal. The insurance company wanted a infusion date by infusion date appeal, not a general appeal. Instead of getting one request and one appeal for service, they wanted nine, one for each treatment...I took it upon myself. I cleared it up, but it took a year of my effort to get the insurance company to review the case and pay [inaudible 00:20:15]. I had to do that myself, and it took a year.

That's what I'm talking about when I say I'm the gosh darn patient. Why am I having to do this? Now, I know, my mother was one of them. When she was alive, she'd drive me crazy. She'd be sitting there, in front of a check book, writing the check out for the bill that the hospital sent. I'd say, "Why are you doing that? You don't even know if that was reviewed by the insurance company. Call the doctor and ask them. Don't just send them a damn check. If you owe this money, you'll pay it, and we'll send them a check. Come on."



White Patients

African American Patients

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"The doctors do that, yeah. I'm just saying that I think that the health insurance—I got a few calls from the health insurance last year, saying, "We have independent doctors or independent medical professionals who want to make a diagnosis of your condition, separate from your primary care physician or other doctors. Then, we'll discuss it with them and then hopefully come to a consensus as to what is best for the patient."

"The insurance companies wanting to—or I assume that they have to—their control over the pain management piece. Them wanting to make sure that nothing happens. It's more difficult to try and—for the insurance company to focus.

3

"It seems like we pay a lot, but we don't really know, "Is that really helping me? Or is it making sure they have enough papers or ink?" Like that.

"I think that was just about the time [social worker name] was leaving, so she wasn't able to help us at that point but we did have Annalise and there was a lot of bills that needed to be paid, and there was much confusion with the third-party billing for the hospital. Boy, that was a mess. That one, they really need to get that—they need to improve in the billing area because you didn't know—when I was going through it, when I would call up they would have these different codes so I had to learn their internal codes so I could figure out what bill that they were talking about and what date it pertained to and then find out that some of it was submitted, some of it wasn't. They didn't put down that she had a secondary insurance, and it caused a lot of bills to accumulate because I couldn't do everything. I was like okay, I can't get to that right now so I let them pile up nicely, sorted, organized them, and I called the various departments to find out that no, this department handles this. That department, we don't handle that area. This is a third party only for these doctors.



Possible Intervention Areas

Transparent Billing

Clear indicators on insurance bill or payment guidelines can clarify the implications of insurance bills.

Reinforcing Financial and Payment Guidance Programs

Programming tailored to comprehending insurance bills may be provided to ease patient concerns. Personal guidance with financial advisors would also be helpful.



Transportation

- ◇ Geographic distance and region influences the care of cancer patients
- ◇ Increased travel burden linked to worse patient outcomes
- ◇ Patients traveling 50 miles more likely diagnosis of advanced cancer ⁶
- ◇ Patient Sample specific issues
 - Transportation showing up reliably
 - Long travel distances





My treatment was so long, I was there for such a long time that I would miss my ride.

Interviewer: Okay. What did you do—

Interviewee: Then we had to try to figure out a way for me to be able to get back home, because it took so long at the other place.

Interviewer: Right. What was the solution that you came up with?

Interviewee: Most of the time, we had to call my case manager through my insurance company and get them to send someone.

White Patients

1

'If you wanna go to one of the support groups, you gotta go to Center City 30:02, and for some people, that's hard.

2

'The unfortunate thing is we live in New Jersey, so it's crossing over the bridge all the time, which is not always an easy fact.

African American Patients

There are places that will—that are transportation for you with CCD Connect Vans, and everything like that. I've tried that before, and they are more than unreliable. It's disgusting what they do. I don't know what they do. These are people with disabilities, and things like that. You have to wait three hours for them to come and pick you up, that kind of thing.

It's very unreliable. They pick you up late, and then they drop you off, and then they pick you up real, real, real late. My cancer diagnosis, the first one in 2000 and—[audio cuts out here - 11:11] had that. [Laughs] I went outside to the hospital and I waited. I waited and I waited. I needed somebody to talk to. I needed some medication. Something! They weren't there! They didn't come until almost four hours.



Possible Interventions Areas

Patient Committees

Create a committee with patient members having ability to offer feedback to help construct a more patient centered system

Have outside company conduct an analysis of the implementation of these efforts

Outside Company Alternative

Another alternative would be to have outside company provide cheaper and reliable transportation that is subsidized



Distrust and Dissatisfaction

- ◇ Patient relationship with provider another major barrier
- ◇ Patients concerned about perceived physician conflict of interests
- ◇ Patients want physicians to gain understanding of their specific needs
- ◇ Patients wanted physicians to do a better job of making them feel comfortable





'That decision is made by some insurance broker or some—I think that, for instance, our primary care physician is more interested in what our health insurance thinks about them than what the patient thinks. That makes me less inclined to trust the doctor. He's in the [Hospital Name] Hospital system. I think that he's very interested to have good standing in their eyes. The patient is of less importance.



White Patients

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"Well, I think with the things I mentioned, I think that if the doctor can get the patient to—if the patient can trust. If the doctor is being inquisitive and will try to find out the best treatment for that patient so that the patient doesn't necessarily feel like one of a million, but actually a unique case. I think that is something that is really assuring. If you feel like your neighbor has the same condition, and the one across the stress as well, and you all get basically the same medicine, then you don't feel acknowledged by the doctor. I think then you lose trust.


2

"I do think it's important how you deliver the message. I don't think it should be over the phone. I think people should be encouraged not to be alone. I think you deliver the message, and then you have—but, "This was the treatment plan, right? This was what we're gonna do. Like this is the reality, and I'm on your team, and here's how we are moving forward."

African American Patients

"Well things could be a heck of a lot different if health care providers weren't coming in with this arrogance. Cause that's what I saw. It was arrogance. Like, "I know more than you and you shouldn't question me. I'm telling you what you need to do moving forward and that should be it." That mentality, it's not very good. It does not make patients feel... I: Respected? P: Respected

It doesn't make them feel comfortable with you. It doesn't make them feel that you are looking at this from this patient sitting in front of you. It's all about numbers. So is that what I am? I'm just a number






Possible Intervention Areas

Empathy Training

Physician training focused on emphasizing importance of delivering empathetic care.

Patient Care Checklists

Creating a checklist with patient input of key things that physicians should do or be aware of when speaking with cancer patients



Issues with Information Navigation

- ◇ Patients face difficulty interpreting doctor's recommendations due to setting and circumstances
- ◇ Communication barriers
- ◇ Many patients are either not aware of available resources or face barriers utilizing them
- ◇ Providers are often not coordinated





'I don't think they talk to each other. Even when the pain medicine was being changed, one doctor didn't want to do it because if too many doctors are involved in it then you're gonna get the wrong medication because they don't really communicate. But that's not really what they do. They should, but they don't. Even before I can get my operation done in November, while we were waiting for my hemoglobin to go up, no one was communicating with each other to tell me nor the hematologist, you know, whatever steps we're gonna take if I can't ever get the operation. What are we gonna do? So they need to learn to communicate better. They're all in the [health care] system. I only see the [health care system] doctors so there's no reason for the poor communication

White Patients

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' I was very interested in the massage part of it, I just haven't been able to connect successfully with the individual that does it there. And um, um, [hospital name], I do have a card, it's just a matter of getting the card, and actually making the phone call and setting up the appointment. But they did, somebody did speak to me on one occasion of the other avenues that you could take

2

' the social worker that made me aware of the different therapies, and even possibly the nutritionist, um, it would be nice, especially since you are being treated for a long period of time while you are there, um, for those people to approach you and introduce themselves to you. I have not met the person who does the Shiatzu massage or any of the other, besides the nutritionist, and that would be a good place to start. The people are there, and you want the patients to use them, well make it easier on the patients meet them by having them introduce themselves.

3

' I don't think we explored what was available. I think that's part of it. I know there's more things available, but we really haven't—the one thing we do take advantage of is a valet parking. Other than that, I don't think we've taken advantage of much of anything. We haven't researched it. It's probably our own fault. She has researched some of it. She did get a wig. She had a very sad experience with the store at the Perelman Center. That turned out to be—she has one, she doesn't wear it anyhow, so she's not worried about it. The hair loss is the least of her worries. She knows it'll grow back. I think we just haven't taken advantage. I know she's done some research and that there's some things available. We just haven't really taken advantage of any of it.

African American Patients

I think that's something because when I went to call Health Aid for healthcare, a lot of things, they didn't know what I was talking about. I didn't really get good advice. It was more like I needed to know the question to ask before they could give me the answer instead of me saying this is what I'm experiencing. What is available? We just got Health Aid about a year ago. We didn't know that we coulda had a home health aid each time she was outta the hospital that could be transitioned. When she's in the hospital and she comes out, there's a lotta things now that you hafta do with the aftercare on top of the normal care that she's receiving. There wasn't any—a lotta preparation for that, and that was time lost

So they told me about things on the side, a therapy program. And I haven't been able to take advantage of that because I am drained and I can't make it there. But, you know, now I am using the, you know, 5mg pills but also learning meditation and breathing through it. I just started that and that also came from the support that...the information also came from the support program

I just think that it should be more—for me, personally, I think there should be more organizations like Unite for HER.



Possible Intervention Areas

Physician Accountability

Upon diagnosis, physicians may provide a set of personalized resources that are provided for patient based on their background and needs.

Patient Accountability

Mandatory intermittent check-ins by a patient social-worker or advisor pinpointing what resources have and have not been used will remind patients to utilize available resources.

Assessment of Patient Preferences

Prior to the treatment continuum, physicians may evaluate patient preferences to best tailor their provision of care.



Issues with Daily life Maintenance

- ◇ Patients are often fatigued
- ◇ Patients are in need of assistance with housework such as cleaning and cooking, as well as taking care of family members and children
- ◇ Patients are many times unable to keep up with work, and as a result endure financial instability





MANNA MEAL

SO THE HUNGRY CAN EAT

unite **WOMEN** HER





' it's just ongoing daily life and how the disease interferes with that. For instance, we plan a family vacation with our children and grandchildren every summer to go to Cape May. He finished with chemo back in March. It was like he finished with chemo in March. We thought we would be in an okay place for a while. Then, he was in the hospital in April as a result of his blood count going down low enough to need transfusions. He finished with that. Then, we started thinking about going away. We were being very optimistic and happy about that. Then, he started not to feel well. He had severe pain. As a result of that, they decided they would put him on morphine. He started the morphine as we were getting ready to go away. The end result with that was that between the morphine and the other drugs he had to take to bypass the complications of morphine like the Zofran and things like that made him very ill.

He went on vacation, but it certainly wasn't the vacation that we had planned. There was a lot of crying going on, a lot of fear of where we were gonna be next.

White Patients

1

'I think the biggest thing is, most people when they're supporting a person with cancer is juggling many other things. I have cancer first and impacting—I don't have cancer so it's not impacting my life from a physical stand point, but it is from emotional and from everything else.

2

'I think we just tried to keep things as normal as possible. There were probably things available, but the kids—we have a certain length in the summer with the kids. I think we just tried to stick to our normal program as much as possible. My son-in-law has kept the kids very, very busy with basketball camps and different things. As far as that goes, we just tried to keep things as normal as possible. I guess there wasn't a lot of time for a lot of other things.

African American Patients

Almost like it was hard to like—you don't feel like doing anything really, like fixing anything to eat, bathing. Just everything was just a challenge. It was a real challenge. Then the very worst part was the numbing in my fingers and in my toes, which I still have right now. I've still got to get more treatment. Like I said, there's nothin' you can do, because what they're giving you is something that you need. It's just like you kind of like try to deal with the side effects. Like I said, it's very challenging.

'Now, I'm not up against it this minute, but I have always been a person who has been concerned and attentive to my financial situation because I've never married. I live alone, and I don't have that fallback, to where well, honey, you're gonna have to work overtime this week cuz pop's not able to go to work. If pop doesn't go to work, pop doesn't make any money. My financial concerns have always been foremost in my mind, from the time I was 20. I knew I wasn't getting married, and I knew I wasn't having kids at that age. Lo and behold, that's what happened



Possible Intervention Areas

Stress Relieving Programs

Patients enjoyed shiatzu and acupuncture therapies. Perhaps introducing other coping mechanism may be found useful

Affordable Household Help

Affordable and available assistance options with household activities including cooking, cleaning and perhaps babysitting would relieve stress experienced by patients

Established Communication between Provider and Place of Work

Communication established between patients place of work and providers would ensure that employers fully understand their circumstances




3

Next Steps

What now?



What Next?



Get patient
Feedback

Analyze &
Evaluate
Current
Interventions

Pose new
interventions



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