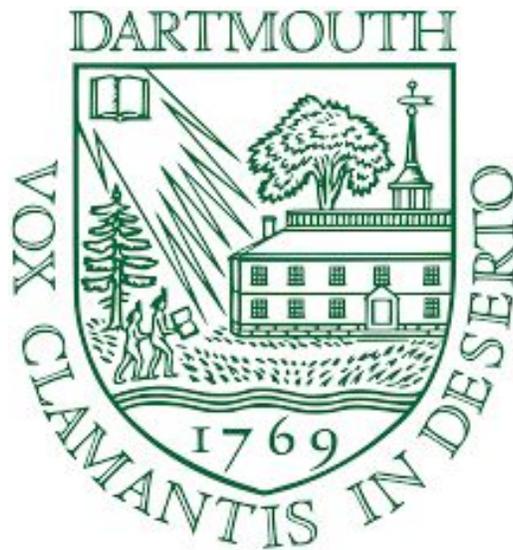


Assessing the Barriers to and Facilitators of Effective Care for Rural Cancer Survivors
Transitioning Out of Active Cancer Treatment Back To Their Primary Care Providers (PCPs)



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Literature Review

Rural populations are often faced with a plethora of issues and so for our paper we focus on the barriers and facilitators of effective care for rural cancer survivors. More specifically we have decided to focus on cancer patients transitioning out of active cancer treatment back to their primary care providers. This is an important topic for our time as most people at this point know someone who has been affected by cancer. This paper enlightens the problems facing patients recovering and transitioning back to society by going over some of the common themes in current literature as well as our own methods to combat the issues at hand.

From a high level we begin with the question “why choose to focus on life after cancer?”. The answer is simple; post cancer treatment remains a major step in the recovery process and transitioning patients from their specialty doctors to primary care must be carefully thought out. (*B.B Franco et al., 2016*). What most transitioning patients struggle with is the insecurity of leaving their specialty doctor. Most believe that their general care provider will not understand the nuances and intricacies as well as a specialized doctor. In other cases, primary doctors may also not be able to handle the full load of a transitioning patient. Depending on the cancer and patient there is a lot of new information to absorb and this is a lot for any doctor to handle. (*B.B. Franco et al., 2016*). In discussing with Jenna, our contact at the Norris Cotton Cancer Center, she shared similar concerns and furthermore thought that this type of disconnect could be worse for rural cancer survivors. This is because the current solution for urban areas is to create more

appointments such that patients can develop a trusting bond with their PCP however in rural areas this can be difficult. (*Charlton Mary et al., 2015*). Rural patients often struggle with transportation to the hospital because they live so far away and can't afford to see their PCP's as much as they would like. A potential solution for this is to implement virtual appointments where rural patients can more easily communicate with their PCPs over the phone however Jenna mentioned that there is a lot of bureaucratic steps before that can happen. For example, how the doctor taking the call will be paid as he is still on the "clock".

Another theme we found most prevalent in current literature was the troubling perspective society has on rurality. In the article, "Urban Residents Views of Rurality and Contacts with Rural Places" (*Willits Fern et al., 2010*) they argue that the vast majority of people misconceive rurality for an area that is secure and for the most part well; though not monetarily wealthy. This view stems from the little contact most people have with rural areas. For most people, traveling into rural areas are for times of vacation, and or visits family/a childhood home. Though the brief amount of time they spend away from urbanization may seem nice and tranquil, it is not sufficient to see the underlying problem of isolation. They miss the wide range of social and economic issues such as: high unemployment rates, lower per capita income, high crime rates that sometimes mirror urban counties. Most who do volunteer their efforts believe that helping rural counties means promoting traditional extractive industries such as farming, forestry, and mining to enhance the economic viability of rural areas. But in Pennsylvania, where this study takes place, there are less than 43,000 farms which in other words mean less than 4 percent of the rural population of the state even live on a farm (*Willits Fern et al., 2010*). This same pattern of misconception can be seen in rural areas throughout the United States. The views

people have towards rurality is a problem for effective rural cancer care because most hospitals around the country do not prioritize rurality for this reason. NCCC is one of the first cancer centers to have received funding and is currently launching an active study to help transitioning rural cancer survivors. Though, NCCS is taking a strong initiative in the Northeast this topic remains an important gap in the literature. If the perspective towards rurality and more specifically rural healthcare remains generally positive, then it will be very difficult to amass the appropriate amount of resources to solve our question of promoting effective care for transitioning rural patients.

Breakdowns in communication can lead to poor continuity of care, delayed diagnosis, polypharmacy, increased litigation risk, and unnecessary testing and therefore can decrease the quality of care. This is especially true for those in rural settings where communication is less transparent. Through the cancer patients transition to survivorship, a key aspect lies in the communication and relationship of the Primary Care Physicians and Specialists. Long-term follow up care can be fragmented, uncoordinated, and in some cases absent. However, this effective communication is vital for accessing patient records, updating cancer care recommendations and keeping in touch with oncology specialists (*Hoffman, 2010*). Often, the long-term follow up patient care has been seen as fragmented, uncoordinated, and in some cases completely absent. In the article “Transitioning to Breast Cancer Survivorship: Perspectives of Patients, Cancer Specialists, and Primary Care Providers”, survivors reported communication to be a main issue (*Hoffman, 2010*). Those who did not have a trusted point of contact felt abandoned and as if they were “falling through the cracks”. Patients feel more at ease with the

oncologist and therefore they need to stay actively engaged to address a patient's needs as they begin their transition.

There has been discussion about implementing another means of communicating with patients that don't have quick access to healthcare. According to an analysis by the Pew Research Center, Rural residents live on average 10.5 miles, which appears to be twice as far longer than people in urban areas (American Heart Association). This places a large burden on cancer patients as they begin to transition to survivorship, and keeping up with follow-up appointments. Researchers have been studying to find a way to make healthcare as accessible to the rural population. A means of communication that has been implemented is telecommunication technology to provide remote diagnosis and development of treatment plans. It involves a telephone or video call to provide remote patient monitoring. It expands their patient service area and increases the rural patients access to the specialists they need. Although this may seem plausible, it is limited by the shortage of qualified healthcare professionals. Due to their heavy workloads, there is limited time for these specialists to find additional time for check-ups through telecommunication networks. Specific to this study, the cancer patient's PCP and specialist would encounter schedule complexity and monetary issues. If an additional appointment is set up to smooth the transition, a few logistical questions must be met before further action. The doctor's time is valuable, so someone must be paid when considering extra work hours. Also, it offers technology restrictions to the rural population that might not have easy access to high-tech software.

When patients develop long-term relationships with their provider, they build trust and knowledge about their medical history to easily assess warning symptoms. They provide a form

of reassurance and expertise in a field that PCPs do not necessarily obtain. Since many survivors believe PCPs lack the oncology expertise, patients may experience difficulties transitioning due to psychological issues. On the other hand, specialists reported to struggle with discharging survivors due to protective relationships. Patients, oncologist specialists, and PCPs all strive for improving care of these long-term survivors as they face feelings of abandonment. Specialists recognize that the transfer to survivorship is necessary but concern about trusting other providers and letting go cherished patients.

The underlying problems that we must address to improve the lives of healthcare for all despite the distance is the barriers to and facilitators of effective care for rural cancer survivors transitioning out of active cancer treatment transitioning out of active cancer treatment back to their primary care providers (PCPs).

Research Question

Dartmouth Hitchcock's Norris Cotton Care Center is one of the largest cancer centers in the Northeast and has committed a portion of its resources to transitioning cancer patients. Because the Northeast is predominantly rural this issue of transitioning rural cancer patients is ever so more important. Most studies currently focus on transitioning cancer patients however do not take into account that it is so much harder when patients are from rural areas. Thus, the formal goal of this paper is to assess the barriers to and facilitators of effective care for rural cancer survivors transitioning out of active cancer treatment back to their primary care providers. The following methodologies and interview questions are thus created with rurality specifically in mind however in terms of generalizability the data generated may be adopted to other transitional cancer studies across the country.

Methods

This study utilizes a largely qualitative approach. Data will be collected from respondents through an in-depth interview, which will be conducted in person as well as through the phone. It will be designed as a semi-structured in-depth interview to gain depth and build rapport with the respondent rather than using a more straightforward question and answer format. The interviews will take place after the patients' third check up with their oncologist to give time for the patient to develop an opinion towards the situation. To conduct this interview, a few materials will be required. An in-depth interview will not possible be without an interviewer, so a person must be present to ask the questions both in-person and on the phone. They should also bring at least one recording device, but it is recommended to have a back-up recording device handy to be safe. It should be conducted in a private room to ensure privacy rights, and the consent forms must be present and signed before the respondents consent to participate.

This designed method brings a number of advantages. The in-depth interviews can provide detailed information into each patient's experience. It will help create a comprehensive picture of the patient's attitude and behavior towards a situation, while understanding the sensitivity of the topic. It is considered the best for response rates, population coverage, and quality of measurement, but is considerably more costly in terms of time and money. The use of in depth interviews minimize nonresponse and maximize the quality of data collected. It allows interviewers to clarify statements and ask for more complete answers while getting a sense of their tone and delivery through verbal and non-verbal cues.

In addition to the many advantages of the qualitative approach, the design has a few disadvantages that must be considered. First and foremost, it would be far more difficult to

conduct and analyze results through in-depth interviews. It requires significantly more time, money, and effort to conduct, review, and analyze the data. Due to the personal nature of collecting data in qualitative research, this method can present itself as a negative component of the process. Although having individual perspectives and instinctual decisions can lead to incredibly detailed data, it can also lead to more generalized or inaccurate data because of its reliance on researcher subjectivisms.

The study tries to measure the relationship between two key variables. The independent variable measured is the type and stage of cancer. Since each type/stage of cancer requires more or less visits to the hospital, it will measure the severity of care that is necessary. Another independent variable is the proximity to the hospital to measure the rurality. This will be operationalized by the area codes. We want to measure how the independent variables affect our dependent variables: emotional state, ease of transition, and chances of relapses. The emotional state will be measured by their subjective relationship between their PCP and Oncologist. Also, we will examine their perspective and experience of transitioning from their Oncologist to their PCP. Lastly, we are interested in their chances of relapses due to the barriers of care. This can be the ultimate effect of the lack of essential check-ups and communication.

We are proposing a non-causal relationship: living in rural areas doesn't inhibit patients from transitioning out of cancer care successfully. Although it can be done effectively by some, it presents itself as a burden to many others. Therefore, it is directly dependent on the individual experience. Rurality is not a direct cause of ineffective cancer care, however, it is closely correlated to the transition and barriers that may occur.

The subjects of the study are the rural cancer patients in the Northeast region of the U.S. More specifically, we are focusing in on patients that are admitted to DHMC that commute there for regular appointments with their oncologists. We will recruit patients by looking at DHMC files of admitted patients and gather their area codes to filter out the patients that come from rural area codes. This will direct our attention on our target population and allow us to make comparisons based on the patient's home location. Since there are 9 area codes that are considered "rural", this will allow us to assess how distance factors into the barriers of transitioning out of cancer care. Along with their area codes, we obtain the patients' contact information such as their home phone number and email address. We will further use these subjects to get in touch with the patients to interview for our study.

Since we are analyzing a selection of patients in rural areas, we won't be able to make any general conclusions about the entire population. DHMC admits 4,000 cancer patients annually. Due to the challenges of in-depth interviews, we won't be able to interview each individual in our target population. Therefore, we will use a non-probability, purposive sampling technique. We will revise the target population with a rural focus. A percentage of rural patients will be filtered out of the 4,000 admitted patients. The revised target population will most likely be within 500-1,000. Within that population, we will form a focal criteria through a quota sampling technique. We will take 10% of the revised population to form in-person in-depth interviews. These 50 interviews will be used as the key informants because they will provide the most detailed information. The remaining population will undergo the in-depth interviews through phone.

Our study will utilize an inductive approach when analyzing data. Since we are focusing on a percentage of the target population, we will use that evidence to form a general conclusion about the rural population. Through in-depth interviews, we will gather the specific observations and search for patterns to make general conclusions.

Our study will be longitudinal because though we may only be interviewing individuals, we hope to apply our data to the entirety of rural cancer survivors. Thus, it is best that we analyze our data over time. Our data will be collected after every interview in the forms of recordings, detailed field notes, and transcriptions.

In terms of generalizability, this study definitely can be used alongside other studies in a similar field. We only care about the transitioning barriers and fluidity of the process but our data will include much more than that. It'll include patient experiences dealing with their cancer, thoughts on transitioning factors, and even support groups. Due to the nature of in-depth interviews there will always be a plethora of information garnered from the 30+ minutes session. Our study is also reliable because in depth interviews dive into the details of the experience. Hence we will not only get the first layer of information from the interviewee, but most likely also the causes and reasons for why they feel a certain way towards the question asked. This study finally has good validity because we have taken careful measure to not probe aggressively, hence the interviewee is kept comfortable. We also are not introducing any of our own biases and or opinions in any of our questions to keep the integrity of the answers 100 percent the interviewees own.

For our research, we expect the in-depth interview to take at least 30 minutes. The researcher will use an interview guide that consists of open-ended questions. The questions will

be laid out in a tactful manner to play down the sensitive topics. There will be 17 questions to guide the interviewer throughout the process, while opening it up for the respondent to explain their story. The in-depth qualitative interview will be formed to achieve sufficient depth, manage topic sensitivity, and build rapport.

We have several strengths and weaknesses for our study. To begin with the strengths, like mentioned before our study offers great validity. As well as this, I believe it sets itself apart from lots of current literature because in-depth interviews allow us to record not only the answers, but also physical behavior and speech patterns. This allows for even more detail and potential analyses opportunity. It's weaknesses include our concern of finding participant involvement as the interviews take so long. However, with the vast resources of NCCC we don't anticipate this being much of an issue as they already have great participant involvement.

Ethical Issues

When conducting a study regarding a highly sensitive topic, ethical issues must be put at the utmost importance. Because of this we are choosing to ensure ethical clarity through using Belmont's three principles of research ethics: Respect for persons, Beneficence, and Justice.

Cancer is not only a highly personal matter but also private. Thus, in terms of respect for persons we will administer a consent form before we even begin the study. This participant and the interviewee will go over this consent form word for word such that the participant understands what the purpose of the interview is, who will be able to access the information/recording, and most importantly know that if they choose not to participate there will be no repercussions.

Alongside respect for persons, we aim to also preserve the well-being of our participants through beneficence. Our interviews will be conducted in closed, safe environments so the participant is not uncomfortable. We will also take the appropriate steps to secure the recordings and data garnered from the interview such that only those allowed and known to the participant and us have access. Our consent form will also state that if at anytime during the process of the study the participant wants to leave or feels uncomfortable then they are welcome to do so; again with no repercussions. This study is ultimately for the transitioning cancer survivor and so by no means do we compromise that goal at any point of the study.

Finally justice will be kept throughout this study through non-biased decision making. Our interview guide is universal to all participants and though the conversations will most likely differ, the way we approach and handle each participant is fair and equal. The benefits and risks of participating must also remain equal for all involved in the study and all of this again will be laid out in our consent form to the participant.

Feasibility and Significance

In our background research on Dartmouth Hitchcock Medical Center and more specifically the Norris Cotton Cancer Center what stood out to us was the amount of resources the entire organization commits to research programs. Just to list a few, DHMC is committed to not only developing new drugs to combat early stage cancers, or to develop better preemptive strategies, they are also diverting a large portion of their resources towards improving the quality of life for cancer patients. Rurality is a significant problem for DHMC as well because it is the largest healthcare provider in the surrounding 3 states (Maine, New Hampshire, and Vermont). These states are mostly made of rural populations and so there is a real push to improve the

barriers especially for transitioning cancer patients. However, rurality is not just central to the Northeast but is important to current literature as our data can be adapted to help other rural counties.

The dedication to provide quality care just scrapes the surface of what DHMC is capable of and we believe that our framework can help Jenna and her team at NCCC with a solid head start in preparing this study. Our qualitative, in-depth interview framework will be a great fit for this study for multiple reasons. This research project is currently on-going at NCCC, and they have raised a large budget for this specific study. This forgoes the disadvantages of using this method, and serves to highlight the advantages that play to NCCC's strengths. Needless to say, NCCC has the resources to conduct this study, and through this in-depth interview, the team at NCCC will detect the difficulties that may occur while ensuring the proper privacy rights. Although we considered alternative methods, we realize that understanding the patients on a personal level is necessary to better understand their situation which is critical for our study.

Through our framework, we suspect that NCCC will find answers to our research proposal of assessing the barriers to and facilitators of effective care for rural cancer survivors transitioning out of active cancer treatment back to their primary care providers (PCPs). Assessing the barriers will enable NCCC to take the next measures of addressing and improving the quality of care for patients living in rural areas.

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Informed Consent

This Informed Consent Form is for men and women living in rural areas who attend the Norris Cotton Cancer Center and who we are inviting to participate in research to enhance the availability and effectiveness of healthcare.

The title of our research project is: How can we assess the barriers to and facilitators of effective care for rural cancer survivors transitioning out of active cancer treatment back to their primary care providers (PCPs)?

Annie McKenna, Peter Chow

This Informed Consent Form has two parts:

- **Information Sheet**
- **Certificate of Consent**

PART 1: Information Sheet

Introduction

Our project partner is the Norris Cotton Cancer Center (NCCC), one of the nation's premier facilities for cancer treatment and research and one of only 50 National Cancer Institute - designated comprehensive cancer centers in the United States. The Norris Cotton Cancer Center provides a positive environment for treatment, cure, and recovery for patients with all forms of cancer.

I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. There may be some words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me, the study doctor or the staff.

Purpose of Research

Rural populations are faced with the burden of healthcare access, especially through the lack of quality health care professionals and quality of care. More specifically, cancer patients endure more barriers as they often have to visit their specialists located in urban hospitals. Therefore, the purpose of this research is to improve healthcare access for rural cancer patients and assess the barriers as they transition back to their primary care providers.

Participant Selection

We are inviting all adults that live in rural areas of the New England region who also attend Norris Cotton Cancer Center to participate in the research

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. Whether you choose to participate or not, all the services you receive at Norris Cotton Cancer Center will continue and nothing will change. You may change your mind later and stop participating even if you agreed earlier.

Procedures and Protocol

During the interview, the researcher will ask the participant questions regarding their emotional state, transition process, and recovery status. The questions will be qualitatively measured.

Duration

The research will take approximately 30 minutes

PART 2: Certificate of Consent

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research.

Print Name of Participant _____

Signature of Participant _____

Date _____
Day/month/year

Print Name of Researcher _____

Signature of Researcher _____

Date _____
Day/month/year

Interview Guide

Setting: Quiet/Private Room

Time: 30 minutes

1. How frequent do you visit DHMC/NCCC?
2. When did you make the transition from your Oncologist to your PCP?
3. Would you consider the transition to be positive or negative?
 - a. Please explain why or why not.
4. Can you walk me through that entire experience?
5. From your first check-up until your third check-up, have you ever felt any different towards your PCP or Oncologist?
 - a. If so, in what ways?
6. What barriers, if any, have you encountered when transitioning from your Oncologist to your PCP?
 - a. What could have been done to prevent this from happening?
7. Has the distance from the hospital or communication between doctors ever affected your experience?
 - a. If so, describe a time where you had to deal with these barriers.
8. Would you feel more at ease if there was a center closer towards your home? Why or why not.
9. Do you feel your symptoms have settled down since it first developed or have they relapsed since leaving your oncologist?
10. Please walk me through a normal day when you have a scheduled appointment with your oncologist.
11. When you leave the doctors office do you feel at ease?
12. What is your primary means to and from doctor's appointments?
13. When you leave the doctors office do you feel at ease?
 - a. What tends to make you feel comfortable/uncomfortable leaving the doctors?
14. Do you have a close relationship with family?
15. Who has been your primary support system?
 - a. In what ways have they supported you?
16. Do you feel more confident with your oncologist or pcp? Please explain why
17. How satisfied are you with your overall transition?

