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Patient Navigation from the Paired Perspectives of Cancer Patients and Navigators: A Qualitative Analysis

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Abstract

Objective—Patient navigation for cancer care assesses and alleviates barriers to health care services. We examined paired perspectives of cancer patients and their navigators to examine the process of patient navigation. We explored the strengths, limitations, and our own lessons learned about adopting the novel methodology of multiperspective analysis.

Methods—As part of a larger RCT, patients and navigators were interviewed separately. We reviewed interviews with 18 patient-navigator dyads. Dyad summaries were created that explicitly incorporated both patient and navigator perspectives. Emerging themes and verbatim quotations were reflected in the summaries.

Results—Paired perspectives were valuable in identifying struggles that arose during navigation. These were represented as imbalanced investment and relational amelioration. Patients and navigators had general consensus about important patient needs for cancer care, but characterized these needs differently.

Conclusion—Our experience with multiperspective analysis revealed a methodology that delivers novel relational findings, but is best conducted de novo rather than as part of a larger study.

Practice Implications—Multiperspective analysis should be more widely adopted with clear aims and analytic strategy that strengthen the ability to reveal relational dynamics. Navigation training programs should anticipate navigator struggles and provide navigators with tools to manage them.

Keywords

navigation; cancer treatment; qualitative methodology

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1. Introduction

1.1. Overview

Multiperspective analysis is a novel and infrequently used qualitative methodology which can offer a richer understanding of the needs and experiences of two or more individuals. In clinical research, linking interviews of patients with their caregivers (family member, clinician, etc), affords researchers access to information that they might not gather from each perspective separately. This information might include an understanding of relationships and dynamics, similarities and differences in perceptions, and novel suggestions for improving services from patients and others involved in their care [1]. Considering the individual perspective alone is the most common approach in qualitative studies in clinical settings; this method is theoretically logistically and methodologically easier than considering paired perspectives and social networks. However, gathering and analyzing multiperspective data has been the backbone of anthropologic field work; it gives researchers the opportunity to tell a more complete story, but also requires clarity about aims and analytic strategy to allow for the emergence of themes that are greater than the sum of the individual parts.

Multiperspective approaches have been described in studies of palliative care [2], couples' experiences with recurrences of breast and prostate cancer [3,4], and physician-assisted suicide [5]. These studies were designed de novo as multiperspective analyses. However, when a study is conducted to collect perspectives of patients and caregivers separately, there are inherent challenges to subsequently analyzing them together. In this paper, we hope to describe our experience with conducting a multiperspective analysis as part of a larger randomized controlled trial of patient navigation in cancer care.

Patient navigation—the assessment and alleviation of barriers to adequate health care by a specifically-trained person—may help patients complete recommended testing and treatment and reduce socio-economic, racial, and ethnic disparities in care [6,7]. Navigation encompasses several potential forms of support for individuals with cancer. The original descriptions of patient navigation emphasized navigators' abilities to assess patients' needs and help them surmount barriers to care [8]. The focus was on “instrumental” aspects of care [9] – overcoming logistical barriers such as insurance, finances, transportation, communication with medical providers, obtaining information, and coordination [8,10]. Less emphasized has been navigators' roles in providing emotional support to patients and families by responding to emotional distress, expressing empathy, listening supportively, providing comfort, and just “being there” [11]. Patient empowerment or activation may be another component of navigation as navigators encourage patients to assume a more active role in their own care [6].

Relying on patients' perspectives on navigation alone risks having a limited view; patients may not have knowledge of what navigation is capable of providing, what navigators are doing behind the scenes, or navigators' own struggles in addressing patients' needs. Including the perspectives of navigators along with patients provides a more complete representation of navigation. Our purpose here is to report on our experience in applying multiperspective analysis to understanding the process of navigation, and to include the lessons we learned along the way.

1.2. Research Questions

This study was part of a larger RCT of patient navigation in cancer care. The goal of the study was to explore the novel methodological approach of multiperspective analysis using the qualitative data available to us. Since we wanted to use this method to uncover new

findings about patient navigation that were not obvious from our group's single perspective analyses [11,12], our specific research question was: *How does using multiperspective interviews shed new light on the process of navigation for cancer care?* Based on our experience with using this methodology, we summarize its strengths, limitations, and our own lessons learned.

2. Methods

This study was conducted as part of a larger study, "Randomized Controlled Trial (RCT) of Patient Navigation-Activation," designed to evaluate the effectiveness of patient navigators on cancer-related healthcare quality and outcomes. The study was approved by the University of Rochester Research Subjects Review Board.

2.1. Patient Inclusion Criteria

Patient inclusion criteria have been reported in-depth elsewhere [11,13]. Briefly, newly diagnosed breast or colorectal cancer patients were recruited from oncology and some primary care practices across the Rochester, NY community. Once a patient was enrolled in the program, they were navigated through the completion of active cancer treatment for a maximum of 12 months.

2.2. Description of Navigator Intervention and Training

Navigator recruitment and inclusion criteria have also been reported elsewhere, along with a detailed description of their intensive training and supervision [12,13]. Consistent with the original model of patient navigation [6], the Rochester Patient Navigation Research Project (PNRP) navigators were lay community health workers (without medical training) that provided mostly face-to-face navigation. Navigators were trained to initially identify patients' barriers to care, and then use a variety of strategies to address these barriers. Actions included face-to-face meetings, linking patients to social or financial resources, assisting with paperwork, scheduling appointments, and accompanying patients to appointments. Navigators facilitated coordination of care by ensuring that test results, consultation reports, and prescribed treatments were available to all providers at the time of appointments. Navigators notified providers when patients missed appointments or experienced new or changed symptoms. The Rochester PNRP had a total of three working patient navigators.

2.3. Interviews of Patients and Navigators

From May, 2007 to October, 2008, individual semi-structured interviews were conducted with cancer patients and their navigators. The patient interviews occurred at either of the following endpoints: 1) completion of all primary cancer treatment, or 2) one year from participant randomization to navigation. Navigators were interviewed upon completion of their navigation with each patient. The content of these interviews has been published elsewhere [11,12]. The interviews were conducted as part of the RCT; we did not anticipate a multiperspective analysis when designing and conducting the interviews.

Interview questions for the patients were developed and refined by members of the research team. Based on known literature and preliminary observations of those involved in training and monitoring navigators, key questions about the navigation process were identified. Examples of these questions include: *"Was there a specific way that you felt a patient navigator could help you?"* and *"Try to recall a time that the navigator did something particularly helpful. Please tell me about that time. What did the navigator do, specifically? How was it helpful?"* Interviews with patients ranged from 5 to 60 minutes.

Interview questions for the navigators were developed to capture navigators' overall experiences working with patients, barriers that had to be overcome, and relational factors that influenced patient navigation. Examples of these questions include: "*As you reflect on working with this patient, I am sure there have been some high and low times. Can you focus on a high point? A low point?*" and "*How would you describe your relationship with the patient?*" Interviews with the navigators lasted an average of 30 minutes.

2.4. Data Analysis

Our study team included four physicians and two research assistants. All patient interviews that also had a corresponding navigator interview were paired to create dyads (patient and navigator). For all analyses, the interviews were read together as dyads. The research team initially read 2-3 dyads together as a group to iteratively develop a systematic strategy for capturing both patient and navigator perspectives in our analysis. After the initial reading as a group, we understood that our data was limited in that it had not been collected for the purpose of a multiperspective analysis. We decided that this scenario was a realistic one as other researchers may find themselves with access to multiperspective interviews not collected for the sole purpose of being analyzed as such. However, given the merits of multiperspective analysis, we approached the dyads with the question of, "*How does using multiperspective interviews shed new light on the process of navigation for cancer care?*" It was our hope to reflect on using multiperspective analysis by also documenting the strengths, limitations, and our own lessons learned from this experience.

2.4.1. Creation of Dyad Summaries—To systematically develop themes and organize relevant quotations, we created summaries for each dyad. The dyad summaries were free text compilations of emerging themes related to our research question, along with supporting verbatim quotations from the paired patient and navigator interviews. All members of the research team participated in constructing these summaries. We created the first two dyad summaries as a group in order to ensure that all members agreed on this methodology. We used an iterative approach to creating the dyad summaries. Pairs of investigators composed a dyad summary, and the whole group reconvened to review the summaries and emerging themes. In this way, the subsequent reading of dyad interviews and creation of summaries reflected back on the themes that initially emerged. One investigator (AY) read through all the interview transcripts as well as all of the dyad summaries to ensure that the dyad summaries adequately reflected the preliminary data. At the conclusion of this phase, we generated a total of 18 dyad summaries from the 36 transcripts of patient and navigator interviews.

2.4.2. Theme Development—Two investigators (AY and SH) used the dyad summaries to generate a table of themes with relevant patient and navigator quotations. Emergent themes were arranged in a table with supportive quotations from patients and their navigator. One investigator (AY) then re-read all of the dyad summaries to identify discrepancies, ensure a complete list of themes, and ensure that each theme was supported by sufficient data from patients and navigators both.

3. Results

We analyzed 18 patient-navigator dyads (a total of 36 separate interviews). Data saturation was reached after review of 16 dyads. The characteristics of participating patients were similar to the larger RCT sample. There were a total of three navigators in the Rochester PNRP. Each navigator worked with multiple patients. Table 1 provides a summary of patient and navigator demographic information.

3.1. Struggles of Patient Navigation

Having reviewed individual analyses of patient and navigator interviews [11,12], we wanted to use a new multiperspective approach to elucidate novel findings that might not have been apparent in the individual analyses. Relational themes of struggles readily revealed themselves as information that we could not have learned had we relied just on single perspective interviews. We discovered three themes of struggles (Table 2) from our paired analysis addressing the question, “*How does using multiperspective interviews shed new light on the process of navigation for cancer care?*” Since the navigator interviews tended to be longer, themes were repeatedly emphasized in navigator interviews, but less frequently mentioned in patient interviews, indicating a situation in which having dual informants was particularly valuable. The theme of *imbalanced investment* was a struggle that was particularly difficult for navigators. The navigators felt a tension between being an advocate for patient autonomy on the one hand, and feeling personally responsible to promote patient decisions consistent with guideline-concordant care on the other hand. Navigators gave multiple examples of how deeply vested they became in their individual relationships with patients. Yet the navigators worked with multiple different patients simultaneously, in a cancer care setting that almost universally sent the message of “fighting cancer” by promoting evidence-based treatment protocols. Therefore, when navigators encountered patients who opted to go against medical advice, they struggled with how to continue to support the patient’s decisions. To the navigators, these patients sometimes seemed less vested in their cancer care than the navigators themselves.

One dyad exemplified the struggle of imbalanced investment. A patient with breast cancer had a mastectomy, but opted out of hormonal therapy because she believed it would increase her risk of a myocardial infarction (MI), and she feared an MI over anything else. From the patient’s interview, this was not a difficult decision for her. She was comfortable with having a mastectomy alone. She gave no indication of any realization that the navigator was struggling to continue his support of her decision. The navigator described the process he went through, first wanting her to speak with her oncologist, then trying to change her mind, and finally reconciling her decision with his role as a supportive advocate (Box 1, Dyad #7).

In another example highlighting the theme of imbalanced investment, the navigator struggled to reconcile the patient’s decision to opt out of treatment with her own belief in standard medical treatments. The navigator had feelings of anger toward the patient that she recognized as misplaced. The patient was too overwhelmed by the care of her chronically ill daughter to focus on her own medical needs. The patient said little in her interview, and nothing about her decision to stop treatment for breast cancer. Instead it was from the navigator’s interview that we learned how the patient “decided after one chemo treatment that she didn’t want anymore of the drugs into her body...she wanted to leave the rest up to God” (Box 1, Dyad #12).

Another category of struggles in patient navigation was *relational amelioration*. In the dyad that best exemplified this theme, we witnessed that the struggle had two layers. From the patient’s interview we learned that her struggle was the extremely adversarial relationship she had with her oncologist after experiencing a side effect from chemotherapy. She admitted to having little trust in her doctors, and was very angry at the lack of response she got from them. From the navigator’s interview we learned that along with the adversarial relationship between the patient and oncologist, another struggle arose for the navigator in balancing her support for the patient without passing judgment about the patient’s medical provider, and potentially making the situation worse. The navigator had to find a way to simultaneously validate the patient’s feelings without creating more tension in the patient-oncologist relationship (Box 1, Dyad # 14).

3.2. Needs Identified

The second set of themes to emerge from our multiperspective analysis underscored what we had already learned in our review of patient and navigator interviews separately [11,12]. We found that patients and navigators have general consensus about the most important needs for patients during the course of their cancer care. Patients' needs as described by patients themselves as well as their navigators were characterized as *emotional support, informational support, and accompaniment* (Table 3). This in itself was not a novel revelation. However, when we read patient and navigator interviews together as dyads, it became clear that the themes of emotional support, informational support, and accompaniment, while they materialized in all interviews, were characterized rather differently by patients and navigators.

This difference in how patients and navigators described the same need was most obvious in our analysis of the most commonly expressed theme—emotional support. Interestingly, patients rarely expressed emotional support as an initial expectation of navigation, but realized it as an unanticipated, emerging benefit once the relationship with the navigator was forged. While highly valued, patients often discovered their need for emotional support from the navigator “after the fact.” In contrast, navigators often identified emotional support as one of their roles from the beginning of the relationship. Emotional support for some patients took the nonspecific form of “just being there,” “a supportive presence,” or a “comfortable friend” to talk to. For navigators, providing support was seen as part of their job, yet they described a personalized, supportive process that took each individual patient's unique situation into account (Box 2, Dyad #12).

For patients, navigation not only offered emotional support to them, but often also to their family when dealing with the patient's diagnosis of cancer. Many patients were effusive in their appreciation for navigators taking time to connect with other members of their family, and there was the sense that the whole family was receiving navigation. When navigators spoke about patients' families, they seemed unaware of how much appreciation patients had for the inclusion of other family members. Instead, navigators felt that it was important to learn about patients' families as a way to gauge the baseline level of support an individual patient might have and to gain insight on needs that the patient might be unable to express (Box 2, Dyad # 6). One navigator who worked with a male patient with colon cancer found that her relationship with his wife was her entry point for navigation, “His wife is like his eyes because he can't see...she's his arms, his everything for him. I spoke more to his wife than I did to him because he wanted to hurry up and get it done...but I could see that he was very scared.”

4. Discussion and Conclusion

4.1. Discussion

To our knowledge, this is the first publication to use a multiperspective analysis to understand the process of patient navigation. Our experience with using multiperspective analysis within a larger RCT allowed us to reflect on the strengths, limitations, and lessons learned from our experience with this novel methodology.

It is not uncommon for researchers to find themselves in the position of having multiperspective data available to them that was not initially gathered with the intention of being analyzed as such. This may happen, as in our case, under the umbrella of a larger RCT. Though analysis may be done on the single perspectives, a dyadic perspective may offer a more complete and richer story. When perspectives are paired, novel findings about relational dynamics may emerge.

In our study, had we relied solely on the single perspective interviews, we would have not learned about the relational themes of struggles in patient navigation. Namely, the theme of *imbalanced investment* would have remained elusive. Navigator perspectives alone have demonstrated an internal struggle with patients who did not follow medical advice. It was not until we included patients' perspectives, and found that patients felt comfortable with their decisions, and were unaware of the navigator's struggle that we could see how having navigators deeply vested in multiple patients might take a toll on their ability to support patients' decisions. Although patients and navigators had general consensus on patient needs during cancer care, they described these needs slightly differently. This has important relational ramifications since how navigators respond to patients' needs is an important foundation to the patient-navigator alliance.

4.1.1. Relevance and Application of Multiperspective Analysis—The strength of multiperspective analysis is its ability to generate a deeper understanding of relationships and experiences than the single perspective analysis most commonly used in qualitative research. Ideally, a study is designed de novo as a multiperspective analysis, allowing researchers to analyze and generate data concurrently, with emerging themes reflected in subsequent interviews [1]. In retrospect, we realize that we did not fully exploit the power of this approach by failing to employ an iterative approach to data collection.

Patient navigation was originally designed to assist underserved patients with instrumental tasks such as insurance, transportation, and childcare [8]. Our navigation program was similarly designed to provide such instrumental supports, and so the questions developed for our interviews reflected an instrumental focus. The interviews were relatively brief, and mostly focused on services provided and unmet needs. If designing this same study de novo, our methodological goal would be to use the emerging themes from our dyad summaries to inform our interview questions, and elicit clear narratives from patients and navigators that invited them to tell the story of their navigation journey. Similarly, we would have pursued leads raised by a navigator about a patient and vice versa. We would have sought to elicit perspectives from each side about particular events that either the patient or the navigator described as pivotal. In this way, we would iteratively integrate the views of both navigators and patients into the interview questions. The interviews themselves would then become a way to explore concordance and disagreement in patient and navigator perceptions.

Other features of patient and navigator interviews also reflect our study's limitations as well as more ideal methodological planning. In our study, patients were interviewed by phone shortly after completing navigation. Navigators were interviewed in-person, often months after navigating specific patients. Phone interviews have a different tenor than in-person interviews, and do not allow the interviewer to explore non-verbal cues. Our patient interviews may have been shorter than the navigator interview just by virtue of being on the phone. If planning a de novo multiperspective analysis, we would interview both patients and navigators (separately) in-person within a short time frame of completing navigation.

Our highly differentiated patient sample along with having only three navigators greatly limits the generalizability of our findings. We did not have control over our sample collection since they were recruited for the larger RCT. However, our findings related to the struggles of patient navigation are unique, and consideration of using other navigation sites in order to increase our numbers of navigators would improve face validity.

In summary, lessons learned through our experience of performing a multiperspective analysis as part of a larger RCT are as follows:

1. Multiperspective analyses should be designed de novo. This gives researchers the ability to design a study that iteratively collects data and uses it to inform future interviews that seek concordance, comment, or disagreement in perspectives.
2. Multiperspective analyses are meant to explore relational phenomena. It is easy to transcribe lists of similarities and differences between two sets of single perspective interviews, but interviews should be analyzed within the context of the relationship.
3. Researchers may find themselves in the position of having multiperspective data that was not meant to be analyzed as such. It is possible that no novel findings will be revealed if the interviews are read as pairs, but it is more likely that a richer understanding of experiences and relational dynamics will emerge.

4.2. Conclusion

In conclusion, this multiperspective study improves our understanding of the process of patient navigation. We found that the struggles that most commonly arose during navigation included a sense of imbalanced investment. There was general consensus about needs identified by both patients and navigators, but there were subtle differences in how each group characterized these needs. Additionally, we experienced the merits of multiperspective analysis in exploring relational phenomena as well as the limitations of this methodology when analysis is not conducted de novo.

4.3. Practice Implications

Our study has both methodological as well as practical implications. Multiperspective analysis is a novel methodology that provides richer and deeper findings about relationships than single perspective analysis. It is a methodology that should be increasingly used in qualitative research. Ideally, studies should adopt the methodology de novo, but even within the context of larger studies, multiperspective analysis will often reveal novel relational phenomena.

Practically, patient navigation programs are growing in number, and learning that there is a sense of imbalanced investment in the relationship between patient and navigator has ramifications for future navigator training. Training programs can be improved to better anticipate struggles, and provide navigators with tools to manage them.

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Table 1

Patient and Navigator Demographic Characteristics

	Patients	Navigators
Number	18	3
Sex		
Female	16	2
Race		
White	12	2
Black	3	1
Other	3	NA
Ethnicity		
Non-Hispanic	15	2
Latino	3	1
Cancer Type		
Breast Cancer	14	NA
Colorectal Cancer	4	NA
Education		
<8 th Grade	2	NA
Some High School	2	NA
High School Diploma or GED	5	1
Some College	3	NA
Associate Degree	2	1
Bachelor Degree	3	1
Post-Graduate Degree	1	NA
Marital Status		
Single	3	
Married/Living as Married	9	NA
Widowed	4	
Divorced	2	

Table 2

Themes of Struggles in Patient Navigation

Theme	Definition
Imbalanced Investment	Struggle for the navigator to continue to support patients' decisions when patient goes against medical advice. Patient unaware of this internal struggle for the navigator
Relational Amelioration	Adversarial relationship between patient and medical provider. Navigator struggles with how to validate patient's feelings without passing judgment on medical provider
Context of Relationship Building	Navigator and patient have to forge a relationship in setting of illness, stress, fear of cancer

Table 3

Themes of Patient Needs in Cancer Care

Theme	Definition
Emotional Support	Broad definition from supportive presence, someone to talk to, involvement of other family members
Informational Support	Providing information about cancer specific topics or “insider information”
Accompaniment	Navigator going with patient to appointments, treatments, surgeries

Box 1**Struggles of Patient Navigation**

Dyad	Theme	Exemplary Patient Quotes	Exemplary Navigator Quotes
# 7	Imbalanced Investment	I went in and just said they're taking my boob off, so what. I know everyone said that the attitude you got is unbelievable... I ain't letting it get the best of me	<ul style="list-style-type: none"> • She stopped taking the medication and there was nothing I could tell her to make her change her mind...She would rather get cancer again than a heart attack. • You are there to help them, so sometimes you have to fight against patients to get them to do things that are good for them and they don't see it as good for them at the time... • You can only fight with them for such a short amount of time then you can't do anything else... you have to respect what they decide...Some patients don't do what we hope they do
# 12	Imbalanced Investment	I needed immediate assistance with my daughter who I had living at home with me at the time...I needed her to be placed into a facility so that I could get the help that I needed	It made me feel a little angry at her because she wasn't doing what I think is the right thing, and a lot of people think is the right thing...She was going in a different direction...you've got to put those feelings aside, I don't want to be angry at her.
# 14	Relational Amelioration	I was angry, it's hard for me to figure out why chemo is so good when it does so much harm...the doctor was annoyed that I wouldn't go back, she said you won't get sick, I said I don't believe you	<ul style="list-style-type: none"> • She didn't like her oncologist at all...there was constant clashing back and forth • It was kinda tricky to not say your doctor is not a very good doctor cause I can't say that. I don't know if that is in fact the case...So it's like I am sorry that you feel that way about your doctor. What can the doctor do to make you feel better? In my head I am thinking wow this doctor is not very good with words. • I validated her feelings that she was feeling sick from the chemo because she felt like no one else was

Box 2

Patient Needs—Emotional Support

Dyad	Themes	Exemplary Patient Quotes	Exemplary Navigator Quotes
# 12	Emotional Support	Just being there. Know that someone is there with me, you know...just somebody to talk to when needed to	Having empathy for the person, understanding what it is like to be in their shoes
# 6	Emotional Support - Family	he took time out for my family, ya know, especially my husband who was my caretaker. Ya know, and he took time out and he talked to him and he let my husband express himself. He (husband) was very impressed, ya know, and he was very happy that I did get a navigator for the both of us	She lives with her husband and he was going through his own struggles with diabetes. So, he was in dialysis and so he would come when he could...mostly she would go by herself