

VOICE OF THE PATIENT AND CAREGIVER DURING CHEMOTHERAPY TREATMENT

Executive Summary Report
on the
Patient And Caregiver Experience (PACE) Project

Research Advocacy Network
Advancing Patient-Focused Research

Research Advocacy Network

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Executive Summary

Patient And Caregiver Experience (PACE) Project

Background

Research Advocacy Network (RAN) has years of experience bringing the patient experience into various conversations and initiatives. But, we also have ongoing concerns about how to best capture experiences, particularly during chemotherapy. In addition, we are concerned that needs of caregivers are insufficiently addressed. When we came upon a technology that we thought was worth piloting, we embarked on a project to test it to “capture experiences” and to include both patients and caregivers. This led to the **Patient And Caregiver Experience (PACE)** project.

We feel efforts of this type are important because a deeper and truer picture of the patient and caregiver experience will:

- Allow development of interventions and supports that make treatment experiences more tolerable and successful.
- Allow health care providers to better meet the needs of patients and better support caregivers (allowing caregivers to give better care).
- Help drug developers better understand how drugs affect life, work and functioning, not just benefit and toxicity.
- Help drug developers and researchers have a more complete and accurate understanding of how drugs should be evaluated by providers and explained to patients. This information could also help companies develop better ways to manage side effects and strategies to address needs that have not been identified previously.

Primary Objective

The project’s key objective was to test a method of gathering data that, if successful, could contribute to or deepen the understanding of patient and caregiver experiences during chemotherapy.

Overview

Eleven patients and six caregivers were identified and recruited by Living Beyond Breast Cancer. They engaged with RAN’s interviewer over a 16-week period, during chemotherapy, in the second half of 2016. The interviewing method is described below. Questions were posed each week. Analysis focused on process measures, to evaluate the feasibility of the method. Additional analysis sheds some light on content, to begin the evaluation of usefulness of information, but is limited due to sample size.

The design and intent of the project was focused on gathering information, but was not intended as an intervention. Others may see the approach and be able to envision intervention-oriented uses that make great sense. To be clear, “intervention” was not within RAN’s project objectives nor expertise.

Information-gathering Method

Since the most novel aspect of this pilot was the data-gathering method, it is most worthy of explanation. The data gathering occurred on an online platform hosted by a research firm. It allowed participants to login at any time to see/answer questions. The interviewer could also login any time to see posts, ask new questions, add comments, etc. Key features:

- Each participant was engaged in a one-on-one “conversation” with the interviewer. They could not see other participants, nor even know there were other participants.
- One interviewer conducted all the “conversations”.
- A protocol and discussion guide were in place; additional probes and comments were allowed.
- The discussion guide was set up to present new questions each week and participants were reminded to login each week.
- The “conversation” functioned like an online chat between the interviewer and participant.
- The “conversation”, however, was asynchronous. This means the interviewer and participant were not expected to be online at the same time. The interviewer did login frequently so participants received speedy feedback.

Figure 1: Example of conversation with one participant

The screenshot shows a vertical sequence of messages in a chat interface. The messages are as follows:

- S14Q13 Carol W (Moderator)**: Are there things that you haven't gotten any help with that you feel would help you get through your treatment better? If so, please describe.
- WonderWoman (December 2, 2016, 8:17 AM) said:** I have gotten help, but I am in too much pain. Even with pain meds. I am going to talk to my dr. I do wish I had some sort of "Cancer Robot". Maybe something like Jibo. It would sit on my dresser and i can talk to it to call someone or to order something from "Amazon Prime Now", or play me a song or tell me jokes and smile at me. There are so many things it could for me.
- Carol W (December 6, 2016, 1:03 AM) said:** WonderWoman, First, I'm so sorry to hear about your level of pain. I hope the doctor can help. Regarding the Cancer Robot, I love that description. I can picture it as you wrote about it and it sounds so smart! Thanks for sharina... Carol
- WonderWoman (December 6, 2016, 3:38 AM) said:** Thanks! My husband got me Alexa last night. I love it already. it can order food or any other items and they can be to my door in an hour. Order pizza, talk me jokes, play games and it even has a therapist to talk to lol. It Can call and text my friends and family for me To alert them of an emergency. And it does everything just with my voice. It is very easy to talk to. And there are endless things she can do! I am so happy to have her!
- Carol W (December 13, 2016, 12:52 PM) said:** Hi wonderwoman. What a great idea! That's terrific. I hope you might be able to hop online today to answer this past week's questions. New ones (final batch) are coming out tomorrow Thank<
- WonderWoman (December 13, 2016, 1:25 PM) said:** Thanks I did
- Carol W (December 13, 2016, 1:47 PM)**: Thank you!!

Note: Throughout this report, comments provided on the platform have not been edited for typos, spellings, grammar, etc. Where participant usernames can be seen, they do not tie back to a person's actual name in any way.

Topics included:

- Expectations regarding treatment
- Emotional state
- Functionality (social, physical)
- Work status and ability
- Caregiver/support
- Spirituality
- Money and finances

Also, a weekly assessment included: hospital/ER usage, symptoms, quality of life, number of treatments and place in cycle.

Figure 2: Weekly topics

Week	Topic
1	Expectations, baseline questions (introduction of weekly battery)
2	Emotional state/sense of control, sleep [asked 4 times]
3	Functionality (social, physical) [asked 3 times for comparison]
4	Work [asked 2 times for comparison]
5	Caregiver/support [asked 2 times for comparison]
6	Emotional state/sense of control [Repeat of PART OF week 2]
7	Functionality (social, physical) [Repeat of PART OF week 3]
8	Mid-point: Experience so far vs expectations, how health care team could have prepared them better overall
9	Spirituality
10	Emotional state/sense of control [Repeat of PART OF week 2]
11	Functionality (social, physical) [Repeat of PART OF week 3]
12	Money
13	Repeat or follow-up on aspects of the work questions
14	Repeat or follow-up on aspects of caregiver/support
15	Emotional state/sense of control [Repeat of week 2]
16	Exit: comparison of experience vs expectations; assessment of PACE

Highlights of Results

1. Participants were highly engaged in the process and, while it was not a project objective, many seemed to derive benefit from their participation.
 - a. 15 of 17 participants remained engaged throughout the 16-week period.
 - b. Of the 15 who completed, and therefore evaluated, the project, 13 reported being very or extremely satisfied with the overall experience and the interviewer. Some comments (as they appeared on the board- not corrected for typos or misspellings):
 - i. "This project is great in helping me think through some of the things in life."

- ii. "I felt like there is someone else out there that I could reach out for and that actually listens to what I was going through while I was going through. There is someone that actually cares enough about the non-medical, non-physical aspect of the chemo treatment to do a study for it."
 - iii. "I liked that the questions helped me to think about my treatments from some different angles. I have been blessed with a pretty positive attitude and being part of the project made me feel like I was maybe helping someone else, even though I was thinking totally about myself. It's been a good excuse to talk about me."
 - iv. "I liked being a part of a medical community. I liked having followups because it felt like I was finally telling someone else how I am feeling and how this is affecting my life. It felt like someone was listening. I liked the prompts and questions because they made me self-reflect on things I felt too busy to consider."
 - v. "I look forward to the questiona every wee, it helped me to think of and comment of how I felt with what I was dealing with. I probably wouldn't have thought of some of the things that I was asked. This helped me deal with what I was going through"
 - c. There was some dissatisfaction with the technology. Future efforts should include examination of options.
 - d. Participants perceived that they derived benefits from being part of the project. In a closed-ended question about possible benefits the following were chosen by most participants:
 - i. 13 of 15 selected, "Gave me a place to share feelings, thoughts, or experiences"
 - ii. 10 of 15 selected, "Helped me explore ideas or impacts I might not have otherwise"
 - iii. 7 of 15, "Helped me organize thoughts to talk to health care providers"
- 2. The PACE board provided extensive opportunity to gather data via poll questions, comments, and open-end questions that shed light on caregiving from the patient and caregiver perspective. Most participants provided vivid descriptions of their daily lives, wishes, frustrations, and needs.
 - a. The board presented an opportunity (and the guide included many questions) to address issues that are not typically discussed with health care providers. Participation in such questions was very high and participants were satisfied with the topics.
 - i. Few if any patients indicated that their conversations with health care providers covered emotions, emotional support, and coping; work (paid and unpaid); money; caregiver support; or spirituality. During the weeks that covered these topics on the PACE board, the response rate to closed-ended questions ranged from 97% to 100%.
 - ii. Few if any caregivers indicated that their conversations with the patient's or their own health care provider covered effects of caregiving on other activities and relationships; money; your caregiving roles; spirituality. During the weeks

that covered these topics on the PACE board, the response rate to closed-ended questions was 100%.

3. Caregiving – both from the viewpoint of the patient and the caregiver – was selected as a topic for further data exploration, given the inclusion of caregivers in the pilot and the indication (above) that it is not frequently explored with health care providers. With the small sample size, we have focused more on the types of data that can be gathered than the actual responses.
 - a. Both patients and caregivers listed who they expected to serve as caregivers and who did serve. Comparisons at different points in time, with more data, could identify which types/relationships are most likely to last.
 - b. Both patients and caregivers listed the roles they expected caregivers to fill and what roles were filled. Again, comparison at different points in time may identify the roles that are successfully filled and help determine the likely gaps.
 - c. Caregivers answered questions about communication with the patient’s health care team, feelings of preparedness, ease/difficulty of caregiving compared to expectations, the emotional toll of caregiving, steps taken to manage or cope, etc.
 - d. Open-ended questions addressed what patients appreciated from caregivers and wished they would do differently. Poignant and informative ideas and feelings were shared.
 - e. The format of the board, which provided a method to ask for clarification, allowed deepened understanding to emerge as situations evolved. Here’s one example: “I do wish I had some sort of Cancer Robot. Maybe something like Jibo. It would sit on my dresser and i can talk to it to call someone or to order something from Amazon Prime Now, or play me a song or tell me jokes and smile at me. There are so many things it could for me.” A couple of days later, she reported: “My husband got me Alexa last night. I love it already. it can order food or any other items and they can be to my door in an hour. Order pizza, telk me jokes, play games and it even has a therapist to talk to lol. It Can call and text my friends and family for me To alert them of an emergency. And it does everything just with my voice. It is very easy to talk to. And there are endless things she can do! I am so happy to have her!”
4. The set-up of the process, that spanned the weeks of months of chemotherapy, and allowed patients and caregivers to login at any time (and requested weekly login), provided the opportunity to gather information as events unfolded. We examined patient responses regarding hair loss during the week it happened, thinking that the descriptions might be more vivid than those that would be recalled weeks or months later. A few samples are shown below.
 - a. “I cut my hair into a pixie to help better prepare my kids for what's to come. I feel weird looking like this.”
 - b. “Have not lost all of my hair, but realize that it will need to be cut. I think this makes the "cancer" a bit more real since it become visible to others and to you.”
 - c. “Cutting my hair made it way more real. We tried to make it fun by asking my little girls to help cut off my hair but I was left feeling very sad.”
 - d. “I think I've been doing quite well, emotionally. I got my head shaved last Wednesday and was thinking I might choke up over losing my hair, but I did fine. So glad I don't look like my Dad!”

- e. “The hardest part is the thought that I still have several months to go in my treatment. I have now lost all of my hair, which makes me look so old and sick. I bought a wig but it is itchy and a pain to wear.”
- f. “Seeing my well shaped head! ... I love the feeling of the shower on my bald head! Who knew?”
- g. “Hair loss makes getting new customers difficult since they assume your illness will make you unreliable. Wig helps but it has taken some time to feel confident while wearing wig.”

Key Implications and Next Steps

We are eager to share this report with a variety of stakeholders, for a myriad of reasons described below. Most importantly, we hope that other stakeholders will contribute to a discussion of key implications and next steps. We see this pilot as a conversation-starter.

First, we return to the project’s key objective: To test a method of gathering data that, if successful, will contribute to or deepen the understanding of patient and caregiver experiences during chemotherapy.

- We feel the report and review indicates the pilot produced information that suggests the method may be used in multiple ways to the benefit of patients and caregivers.
 - It allowed patients and caregivers to establish a rapport, provide deep and meaningful feedback, and experience personal benefits.
 - Topics could be repeated at regular intervals for tracking and detecting patterns (e.g., are some weeks/days harder than others?).
 - With a larger sample, the information gathered could be used by various stakeholders to develop interventions and supports, to provide better care, to deepen understanding of the full impact of chemotherapy (on both patients and caregivers), to influence the evaluation of treatment options, and to develop better methods to manage side effects.
- That said, an expansion should only be undertaken with a full comprehension and examination of the associated effort. Perhaps the integration of actual patient and caregiver interventions, so care is improved AS data is gathered, would make the investment worthwhile. Key aspects of investment that may be under-estimated:
 - Recruiting
 - Interacting in a way that builds rapport (this was highly personalized and time-consuming)

We are pleased to work with partners to share our more detailed experiences and enhance work that uses this data-gathering method.

- The exchange produced information on topics that patients and caregivers do not typically discuss with health care providers. This platform is not the only way to gather the information. But, it is a tool well worth considering depending on information objectives and resources,

We encourage incorporating a wide range of domains into data-gathering that is intended to understand and improve the patient/caregiver experience.

- It may be most important to note that talking to and about caregivers is critical and may be missing from many initiatives. The caregiver experience is unique and cannot be gathered from the patient. In addition, patients have concerns about caregivers. Patient outcomes may be improved if caregivers are better understood and assisted and can, therefore, provide better care. And, caregivers may experience their own set of challenges that, if unaddressed, may increase the chances of their own health problems.

We strongly encourage inclusion of caregiving and caregivers, as well as many of the topics we explored within our discussions.

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END OF EXECUTIVE SUMMARY

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