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Motivations, experiences, and aspirations in patient engagement of people living with metastatic cancer

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Abstract

The objective of this patient-led study was to explore the motivations, experiences, and aspirations of people living with metastatic cancer who volunteer in patient engagement. This qualitative study filled a gap in lived experience research about patient engagement by focusing on an oft ignored population – those living with metastatic cancer. We used a patient-oriented research approach throughout the research cycle from proposal development to data analysis. A Patient Partner helped develop the project proposal. We selected a qualitative descriptive design to best align with our patient-oriented research goals. The first author, a peer researcher with metastatic cancer, conducted semi-structured interviews with seven participants. The interview questions focused on why patients with metastatic cancer volunteered in patient engagement, the experiences and challenges they encountered as volunteers and what they wanted to achieve in their participation. The interviews were transcribed by the interviewer with personal details redacted for confidentiality. Optional member-checking occurred with three participants. After the interviews, two participants joined the research team to participate in data analysis and interpretation of the findings. Thematic analysis was used to identify common themes in the transcribed and redacted participant interviews. The resulting themes were contributing fully, creating a better cancer experience, making meaningful connections, giving back, and struggling with the system. These findings yielded theme-based advice for both patient partners and administrators for creating meaningful patient engagement. Further research led by patient partners could contribute to a more empowered patient engagement program.

Keywords

Patient engagement, qualitative descriptive, patient-oriented research, thematic analysis, metastatic cancer, patient experience

Introduction

I (the first author) was diagnosed with metastatic cancer in 2013. A diagnosis of metastatic cancer means that cancer has spread from a primary location to other parts of the body such as lung, liver, bone or brain.¹ It is difficult to estimate how many people are living with metastatic cancer because registries only document stage at first diagnosis, not recurrence/progression.² While often considered a death sentence, people are living longer with metastatic cancers, albeit with indefinite treatment.³ Consequently, there is little to no research written about people living with metastatic cancers. When diagnosed, the best treatment option for me was available but not funded. I accessed this treatment through advocacy and fundraising. After a particularly grim prognosis, I ended up achieving no evidence of disease and have remained so with ongoing treatment.

As a result of my advocacy work, I was introduced to Patient and Family Experience (PFE) at BC Cancer in 2017 and became a founding Patient Partner (PP). PFE at BC cancer aims to ensure person-centred care by

promoting partnerships between patients, families, clinicians and administration.⁴

There are many volunteers in oncology – some are patients themselves. A mixed method study that looked at volunteer job satisfaction of 753 cancer-experienced volunteers across Canada found that satisfaction was high, and four themes related to satisfaction were learning, personal growth, challenge, and giving back.⁵ Another group examined the lived experience of volunteers that helped in a palliative care biography service and found that volunteering was personally rewarding and gave the volunteers a deeper understanding of existential issues and more awareness of other's struggles.⁶

One way of volunteering is in patient engagement (PE). PE at the level of health service design and delivery is essential for patient-centred care. A survey of over 3000 patients across the United States revealed their views about PE and suggested that a vast majority of patients believed that patient representation in health service delivery was important.⁷ A qualitative study about what matters most to stakeholders including patients, clinicians and leaders in Alberta Health Services concluded that a

*“strong collaborative approach and foundation for meaningful patient engagement was required.”*⁸ A systematic review focusing on barriers and facilitators to effective PE strongly recommended that research on the lived patient experience in patient engagement was needed to forward the research.⁹ Consequently, in this study, we aimed to explore more intimate experiences - the motivations, experiences, and aspirations of people living with metastatic cancer who volunteer in patient engagement at BC Cancer. Our research questions addressed why people with metastatic cancers volunteer in PE, what are some of the experiences and challenges they encounter, and what they want to achieve in their participation.

Methods

Patient Oriented Research

Our aim was to collaborate with patient partners (PPs) throughout the research cycle.¹⁰ As such, we recruited a PP to assist with the development of the research proposal and interview guide. Two PPs – referred to as Patient Partner Co-Investigators (PPCI’s) - were later recruited from the participants to aid in the data analysis and interpretation. In this manuscript the pronouns *I*, *me*, and *myself* refer to the lead author; *we* refers to the research team including PPCI’s and the project supervisor.

Methodology

We chose a qualitative descriptive (QD) approach to explore the experiences of PPs in PE.^{11,12} We felt that it was the best option for patient-oriented research (POR) because it was not bound by theory, allowed for storytelling, kept data closest to the source – the patient voice – and could be presented in a descriptive style in plain language.^{11,12,13}

Setting

The study was completed within the context of PFE at BC Cancer. BC Cancer provides comprehensive cancer care to residents of British Columbia through six regional centres and community chemotherapy clinics.¹⁴ PFE works across BC Cancer sites and programs to create PE opportunities. Engagements range from short term to ongoing and can be in person, via teleconferencing/videoconferencing, or by email. As of March 2020, there were 139 partners and 73 engagement initiatives of which 27 were complete, 44 in progress and two on hiatus (Joyce Lee, personal communication, August 20, 2020).

The Behavioural Research Ethics Board at the University of British Columbia approved this study.

Participants

The participants in this study were seven people with metastatic cancer who had or were receiving non-curative treatment and were PPs with BC Cancer. An email invitation looking for volunteers was sent to all PPs at BC

Cancer who met inclusion criteria. The criteria were working age (18-65), diagnosed with advanced cancer that requires more than 2 years of non-curative treatment, PP with PFE at BC Cancer for at least a year, experience in at least one engagement, not end of life at time of interview, and able to participate in an interview. Although we did not use purposive sampling as recommended in QD research,^{11,12} we were able to gain input from a diverse group of PPs with diverse experiences and perspectives in PE. There were two men and five women. Four were from urban locations and three from rural. They had four different cancer types including one with brain cancer. Two spoke English as a second language. Participants had participated in a diverse range of engagements from reviewing patient handouts and clinical trials/grants, to attending focus groups in person or participating in ongoing committee involvement via teleconference. Participants chose their own pseudonyms. The seven participants were Rufus, Troy, Hohoeminsensi, Carol, Peggy, Best Before, and Joan.

Procedure

Participants who expressed interest were emailed an information and consent package. They were given the choice of communication methods for the interview. Three interviews were in person, two were by videoconference, and two were by phone. The data was collected by me using a loosely structured interview. The interview covered three main areas: 1) How/why people became PPs, 2) experiences in completed or ongoing engagements, and 3) future hopes/dreams. The interviews were conducted, recorded, and transcribed by me. Any potentially identifying info was redacted from the transcript. Peer to peer interviews were often very personal making it challenging to control for bias. I used a reflection journal and debriefed with my supervisor when such issues arose. Three participants chose to complete optional member-checking and to discuss emerging themes. Two signed on to participate as PPCI’s and completed the Tri-Council Policy Statement on Ethical Research Involving Humans: Course on Research Ethics.

Data Analysis

The data were analyzed using thematic analysis.¹⁵ I read through all of the interviews several times. The PPCI’s and my supervisor read 1-3 interviews each. The interviews were discussed over teleconference and email. Preliminary concepts, ideas, and themes were noted. Codes for analysis were generated inductively through these iterative reads. I then coded all of the interviews and collated the data accordingly. The codes were organized into potential themes following guidelines.¹⁵ Relevant data was grouped under each theme. A working draft of themes was then reviewed with the other PPCI’s and with my supervisor. Any disagreements in themes or supporting data were resolved by consensus.

Results

Thematic analysis of the transcribed scripts revealed five themes: *contributing fully*, *creating a better cancer experience*, *making meaningful connections*, *giving back*, and *struggling with the system*.

Contributing Fully

Partners talked about their own and other's rich and valuable pre-cancer experiences including having multiple academic degrees, leadership positions, and volunteer roles. Their precancer experiences allowed some of them to contribute more fully in their roles as PPs. Best Before, an experienced PP explained: *"You have a lot of people who have a lot of skills in their pre-cancer lives...there's a real vested interest in just wanting to bring to the table anything."* A newer PP, Carol expressed, *"I think I have some background and skills and experiences that I can bring, and I would like to bring those."* Similarly, Troy shared: *"So I kind of have this energy and this need to, you know, do things that are productive to help grow things. Try and find solutions and that sort of thing. And this is an avenue that I think I can do it."*

Some partners spoke about what it was like to not be able to contribute fully. Carol spoke about what happened in a teleconference: *"Well I just felt that the direction other people were going, I wasn't there. It just was not relevant, and I couldn't, I didn't feel I had anything to contribute. It was a very weird feeling."* Joan explained what happened when the role of PP was not clear in an engagement: *"I don't know what the steps were there, but they didn't seem to have a really clear idea yet of how PP could contribute."* Peggy commented on the potential for tokenism: *"This is what you have to think of when you involve people. You're not just there to have a patient on your board...And don't invite patients to the cancer summit just because you got a mandate."*

All seven participants indicated that they wanted to remain involved as PPs and four indicated that they wanted to contribute more substantially. Joan shared that she wanted something that required more time and effort: *"I would just hope to become more involved and participate in more substantial projects. Something that is more in depth, involves a bigger time commitment, something that's more long term, and just uses more brain power."* Troy expressed that he wanted the opportunity to be a leader: *"I think in the future possibly, see where things go, I wouldn't mind, you know, being a lead on a project or something like that. I think I've got the skill set for it. That could be a good challenge."* Peggy disclosed her opinion: *"So as a patient partner, I'm very clear that I want to be used for serious business and to make serious change and I have a lot of energy and a lot of brain capacity to be involved in that way."* Carol shared: *"I'm thinking I don't want to not be doing anything. At the same time, I don't want to be stuffing envelopes somewhere."*

Creating a Better Cancer Experience

Partners were highly motivated to make cancer care better for others regardless of whether their own cancer experiences were positive or negative. On the positive side, Carol communicated, *"You know maybe my perspective of having had a good experience through this whole procedure...I think there's room for that as well."* On the negative side, Hohoeminsenshi revealed their story of a particularly difficult situation in which they were getting mixed messages from the health care team. As a result, it was important to Hohoeminsenshi to reduce other's suffering: *"I don't want anybody to go through this way, it shouldn't be, and I'll keep looking to any place, whatever wherever I can help."* Rufus, a participant whose mother also had cancer, explained how his mother's recent experience had been frustrating, partly because she did not speak English. He hoped that by becoming a PP he could improve his mother's experience: *"I was thinking that if I was able to contribute more to the journey of the patient, that whatever my mom was feeling could be better."*

A couple of partners had advice for BC Cancer to improve the cancer experience. Best Before felt strongly that PPs should have an impact at higher levels of administration and policy: *"Yes I think as PP we should be speaking at the decider level. If we want it meaningful, we should still do sort of ground work, but I think there should be a heavier tilt to the decider."* Hohoeminsenshi echoed this acknowledging that she did not have the power to make the changes: *"But I cannot do it. But somebody start talking. Then somebody can maybe somehow, someone with power, power, power can help."*

Partners were asked to think about the most important difference they wanted to make as PPs at BC Cancer. They all wished to create a better cancer experience for others one way or another. Joan wanted to help others and improve links:

"Just helping other patients and helping patients accept diagnosis and not being afraid. And improving links between patients and the medical community. I think if we can all connect and overcome our fear and anxiety, I think that would be a big one."

When Troy was asked directly about legacy he responded: *"I think I would like my legacy to be known as somebody who diagnosed with this, dealt with it in a very forthright and very strong manner, and used the opportunities that were available to try to further things for other people."*

Troy also felt strongly that mental health needed to be addressed:

"Mental health is a very big issue that I currently feel is not being given the priority it deserves. One of the things I'd very much like to see is a program that prevents people from suffering the mental health side of the side effects."

Peggy wanted to use her cancer experience to become an advocate for holistic treatment: *"Well I had this dream that*

I'm going to live a really long life and because I've got such a juicy story I'm going to be an excellent advocate... that's my dream." When asked what she would like a fictional PP award for, Carol responded: *"For any contribution that I'd been able to make. It underlies my whole reason for reaching out at all."* Best Before had some strong words when asked what they wanted their legacy to be: *It's definitely that throat to choke. I said it at the various meetings and it's a harsh term because I want you to hear it when I say it. And I want you to remember it, and if nothing else, it's the throat to choke idea... We need that accountable piece."*

Making Meaningful Connections

While the PFE program was not designed for peer support, connecting with others emerged as a significant perceived benefit of being a PP. Joan explained how connections with the PP group was a source of support: *"It's nice to know that there's this network of us out there. If I really needed help, if I really needed someone to talk to, I know where I could turn."* In a similar vein, Hohoeminsenshi recommended patients reach out: *"There's a group like this try to support, try to understand, try to...situation better you know. You shouldn't hide by yourself."* Peggy felt they could learn important lessons about how to live better with cancer from other partners: *"To be put in touch with people who are a similar minded...you know. That is so great to talk to other patients and hear what they are up to when they've had some success."* Furthermore, Best Before perceived that hearing other's stories and connecting in engagements was therapeutic:

"At the same time, I got involved in the PP thing and I thought listening to other people with completely different situations, histories, cancer treatment. There was such a strong commonality for me like that and I think it's the psychosocial part that kinda glues me to that. For me it's like kinda therapy ... 'cause there's other people that are, you know, alive. It's the aliveness of it and the wanting to share umm either cathartic moments or share the relentless frustration with the medical systems. Or it's that part for me that has helped me kinda step around again and allow me to survive mentally"

In contrast to feeling supported by other PPs, two rural partners expressed feelings of disconnection. First Joan said, *"you know it's hard being stuck out here."* Carol reiterated, *"I feel that I'm kind of in this isolated corner of the province...the isolation is really beginning to be noticeable."* A sense of disconnection was not limited to rural partners. Best Before, an urban partner, commented on a different type of isolation, being the only patient on a committee: *"On these committees, I'm the only PP and on some there might be two of us, so there's thinness in the representation."*

Communication methods appeared to contribute to the quality of connection felt by partners. They shared that their engagements were in person, by email or through teleconferencing. They appreciated the flexibility this brought: *"I liked in-person when I was available, but I also appreciated the fact that they were available for the teleconferencing*

(Rufus)." However, partners voiced that they preferred more personal methods, *"Yeah I like meeting face to face whenever I can (Troy)."* This was especially important to Hohoeminsenshi, who's primary language was not English. They said, *"I like more in-person. Face to face much easier to communicate."* Rufus was proudly bilingual stating: *"I speak Cantonese and I speak English. I thought I might as well contribute a little bit."* This allowed them to give a voice to other Cantonese speaking patients. While teleconferencing allows for many conveniences, Carol pointed out that it can present with a significant challenge: *"I find with teleconference meetings that it's very difficult to insert your voice."* Carol also explained why face to face was important for meaningful partner engagement: *"Again when you're face to face, there's things you can do, visual cues or other kinds of cues that can allow other people to be involved, and I think people take more...responsibility to be a full participant in the giving and receiving balances."*

Giving Back

A common motivation for becoming a PP was giving back. Despite their own challenges, ongoing difficult treatment, and uncertain life expectancy, the partners wanted to reciprocate. Joan expressed: *"I wanted to do something to help give back."* Troy similarly said: *"It keeps me feeling like I am giving back a little."* Peggy echoed: *"Yeah it's been very meaningful, I'm sure you feel the same. To give back in a way that will make everything better for everybody."*

While it was clear most wanted to contribute to benefit others, there were reciprocal, unexpected benefits for some partners. *"If I were to say something about (being a PP), I would want to say cancer experience is almost whatever you put in is whatever you get out kind of in a way (Rufus)"* Joan was pleasantly surprised that her participation could make an impact: *"So, I was surprised that somebody like me without a science background who hadn't been involved in the cancer scene for decades could actually make a contribution and, you know, my contribution could be valued."* Similarly, Peggy expressed: *"I left there really having a greater appreciation for the work that they do, and I felt I had helped give them a greater appreciation for what it might be like to be a patient."*

Struggling with the System

The scope and mandate of BC Cancer is extensive, lending itself to bureaucracy.¹⁴ Troy shared how his expectations compared to his actual experience in PFE: *"I thought it would be a little more top down, you know, we tell you what to do. I find this initiative is extremely proactive. And I was a little bit surprised about how proactive it is. How many engagements come out. How much they seem to value and respect the PP experience."* Best Before participated in three ongoing committees and shared: *"I struggle with the monumental uphill bureaucratic and administrative battle in each."* Their greatest frustration was around timeframes in ongoing committees. *"I think the only expectation is the whole timeline thing. I didn't think things would be so grindingly slow. I had the expectation of slightly more momentum."*

Troy explained how it might not be possible to implement great ideas that arise in engagements because of administrative or policy issues. They shared about an initiative aiming to give patients access to their records online: *“And those sorts of things which I don’t believe are really questions that can be answered by people that aren’t largely familiar with what I’m guessing, is the big machine of policy that BC Cancer is.”*

Engagements typically put a diverse group together including patients, administrators, and clinicians. At times, differing agendas of the group members impacted the group work. Troy explained: *“There’s some people that go in with a different agenda than other people ...it seems that basically their main agenda is just vent about things and not work on the given project.”* Peggy concurred and expanded on this:

“I think that for us patient partners we should all be very clear on why we’re doing this. What are we in it for? And there has to be a reason for me the patient partner and there has to be a reason for BC Cancer. And those reasons have to be aligned. Otherwise, it’s just a lot of meeting and coffees and teas and everybody just airing their whatever.”

However, Troy also acknowledged that frustrations due to different agendas are not specific to working on engagements at BC Cancer: *“I wouldn’t really call it a frustration to being a patient partner, that’s a frustration in life.”*

A common observation from the PPs was that they were not sure what happened to their contributions in projects. Troy expressed frustration about lack of feedback: *“I guess if there’s anything...where we’ve sort of been pushed out. I guess that’s a little frustrating. I don’t know what impact we provided, what help we were. So, a sort of feedback.”* Best Before spoke about reviewing patient handouts when she did not hear back after submitting edits: *“Document closure. You don’t need me to sign on whether you took my edits or not, but I would like to know what the end result was and make it evident to me. Give me the feedback loop. That’s what I want.”*

Discussion

With this study, we aimed to explore the motivations, experiences, and aspirations for people living with metastatic cancer who volunteer in patient engagement at BC Cancer. We wanted to know why people with metastatic cancers volunteered in PE, what were some of the experiences and challenges they encountered and what they wanted to achieve in their participation. To the best of our knowledge, this is the first study led and informed by patients with metastatic cancer that focuses on their own experience in PE. This fostered an intimate view of PE. *Contributing fully* was an overarching theme with the word ‘contribute’ being stated in every interview. This selfless motivation surprised us, because all the partners were facing a diagnostically terminal cancer, and most had

limited physical and cognitive reserve. However, all wanted to spend their time and energy contributing.

The motivations and aspirations of patients in PE have not been addressed in previous research.^{7,8,9} A systematic review revealed that barriers to authentic collaboration and empowerment were workload, hierarchies, lack of role clarity, and tokenism.⁹ In contrast, we found the primary struggles in PE to be slow timelines, different agendas and lack of a feedback loop. The review also outlined facilitators for PE including incentives, flexibility, and relationships.⁹ Making meaningful connections, especially with peers, was important to our PPs. Surprisingly, in our study, external incentive was not a priority. If anything, the value of being listened to as a PP was an unexpected reciprocal benefit.

The findings of our study had more in common with previous studies about volunteering. A survey of oncology volunteers with personal cancer experience revealed that learning, personal growth, and giving back were the primary reasons for volunteering.⁵ We too found giving back was a primary motivation, but more self-focused goals such as learning and personal growth were not mentioned by PPs. A study about the lived experience of volunteers in palliative care who helped write biographies for patients found *“motivating factors were a combination of personal interests, existing skills, previous affiliations with the hospital, a wish to expand their understanding of the human experience, and a strong desire to help the community.”*⁶ We too found that the ability to contribute existing skills was important to PPs along with a strong desire to make cancer care better.

Implications for Patient Partners

The implications of these findings can improve PPs’ experiences in PE. In order to feel one is contributing fully, one can share their pre- and post-cancer experiences and look for potential to contribute more substantially over time. In order to improve the cancer experience for all, PPs could reflect on what went well and what could be improved in their own cancer experience. To make more meaningful connections, PPs could reach out and get to know other people on their engagements. PPs should frequently ask themselves if they feel valued and if there are any reciprocal benefits to them. If struggling with the system, PPs should think about how it aligns with their motivations and aspirations. And finally, PPs should ask for feedback from other PPs, leaders of engagements, or the PFE director.

Implications for Administrators

Administrators should be aware of the capacity of PPs to contribute fully and not treat participation with tokenism. They can get to know their PPs and find out what they bring to the table outside of being a patient. They can try to include them more in meeting discussions or envision

more involved roles for PPs, possibly with some additional support or training. To create more meaningful connections, make sure to have a more than one PP on an engagement, and take the opportunity to talk to or email with PPs outside the confinements of the engagement. An important duty is to ensure one is making PPs feel valued. Administrators need to consider if PPs are struggling with systems and find better ways to align motivations and aspirations with engagements. If a PP has a passionate agenda that impacts engagement, perhaps it can be redirected meaningfully. And finally, give verbal or written feedback directly to your PPs even for short-duration engagements.

Limitations

The sample size was small, and it represented a very specific group of people with metastatic cancers who volunteered in patient engagement at BC Cancer. Small size, specific group, and specific setting make generalizability of the findings limited. A convenience rather than purposive sample was used, suggesting that perspectives might be limited. For example, volunteers were highly educated and had experience in business leadership; the voices of marginalized groups might be lacking. The first author completed all of the interviews and transcribed them redacting personal information, meaning that the rest of the research team did not have access to the full context of all of the interviews. In order to be flexible, especially in cases of people with English as a second language, interviews were conducted in three ways – in person, by phone, or by videoconference. The different contexts could impact the findings. For example, lack of visual communication could influence the outcome of the phone interviews.

Conclusion

This patient-led study aimed to explore the motivations, experiences, and aspirations for people living with metastatic cancer who volunteer in PE. It filled in a gap in the research about PE with an endogenous, qualitative approach. The findings yielded advice for both PPs and administrators in PE by focusing on the five themes: *contributing fully, creating a better cancer experience, making meaningful connections, giving back, and struggling with the system*. Perspectives were limited to patients with metastatic cancer and were not representative of the entire group of patient and family partners at BC Cancer. This group includes those with early stages of cancer and family. A more extensive study using a comparative patient-driven methodology could be used to gain insight into this larger group's viewpoints. This could yield weightier recommendations for making PE more effective and meaningful in larger organizations.

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