

# Examining the Process and Effects of Engaging Patients and Family in Health Service Evaluation: Results from a One-Year Prospective Intervention Study

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**Abstract:** *Research on program evaluation in the context of patient and family engagement is highly limited. Collaborative approaches to evaluation (CAE), with their emphasis on evaluators working in partnership with program community members, align well with patient- and family-centred care philosophy and hold great promise in leveraging desired outcomes. In this prospective intervention case study, we tracked a one-year collaborative initiative to engage health care providers, patients, and family members in improvement-oriented needs assessment activities. The findings illuminate the lived experiences of health-care staff, patients, and family members with the CAE process. We conclude with implications for ongoing research and practice.*

**Keywords:** *collaborative approaches to evaluation, health quality improvement, patient and family engagement, program evaluation*

**Résumé :** *Il y a très peu de recherche sur l'évaluation de programme dans le contexte de la participation des patients et des familles. Les approches collaboratives en évaluation (ACE), qui mettent l'accent sur le partenariat des évaluateurs avec les membres de la communauté du programme, cadrent bien avec une philosophie de soins axée sur les patients et les familles, et s'avèrent très prometteuses pour l'atteinte des résultats désirés. Dans cette étude de cas sur les interventions prospectives, nous avons fait le suivi d'une initiative collaborative d'un an visant à faire participer des fournisseurs de soins de santé, des patients et des membres de la famille dans des activités d'évaluation des besoins orientées sur l'amélioration. Les résultats offrent des perspectives intéressantes sur les expériences vécues du personnel en santé, des patients et des membres de la famille dans le cadre du processus d'ACE. Nous interprétons ce que signifient ces résultats pour les pratiques courantes et la recherche en cours.*

**Mots-clés :** *approches collaboratives en évaluation, amélioration de la qualité de la santé, participation des patients et des familles, évaluation de programme*

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Strategic efforts to increase patient and family engagement are geared toward addressing some of the gaps identified in the use of conventional quality improvement strategies (e.g., patient satisfaction surveys, performance monitoring, patient narratives) as well as improving the quality of patient-centred health services (Gilbert & Cousins, 2017). However, there is little research on the best approaches to use when patients and family (i.e., individuals from a family or family unit) collaborate with health professionals and evaluators on program improvement initiatives, including program evaluation. The literature is devoid of insights into the lived experience for patients, family, and health professionals involved in this type of collaborative process, and of the effects on programs (Baker & Denis, 2011; Crawford et al., 2002; Gilbert & Cousins, 2017; Maher et al., 2017; Van De Bovenkamp et al., 2009). Studies that have reported on patient and family engagement experience are generally descriptive in nature and limited to reflections on the strengths and limitations of the engagement process without examining the effectiveness of their engagement approaches or what the experience was like for patients, family, and staff (Maher et al., 2017). Furthermore, most of the patient and family engagement initiatives reported in the literature have been consultative in nature rather than representing genuine interactive engagement sustained over time (Bombard & Baker, 2011; Fudge et al., 2007; Gagliardi et al., 2008b).

Recently, we argued that collaborative approaches to evaluation (CAE) are well suited to the evaluation of patient and family engagement; they provide a means to explore and better understand the processes involved that could contribute to translating patient and family engagement into improved outcomes (Gilbert & Cousins, 2017). The well-established definition of CAE is the co-production of evaluation knowledge by trained evaluators working in partnership with members of the program community (e.g., patients and families, health-care providers) (Cousins et al., 2013). The present study adds to our knowledge about the evaluation of patient and family engagement in program evaluation by tracking a one-year CAE initiative in a health-care setting. We wanted to explore the following questions: What were the facilitators and barriers to collaborative planning and evaluation? What did engagement look like in practice? What were the effects of the collaborative process?

## OVERVIEW OF THE STUDY

### *Intervention and conceptual basis*

We began this prospective intervention case study by creating a Patient and Family Engagement Committee (PFEC) at a psychosocial oncology program (PSOP) in an acute care hospital in eastern Ontario, Canada. The first author, a trained evaluator with specialized experience in health services, led the committee, which consisted of four PSOP staff, four cancer patients, and two patient family members. Participants were recruited through letters of invitation, posters, and flyers distributed by care providers; they were not compensated for their participation.

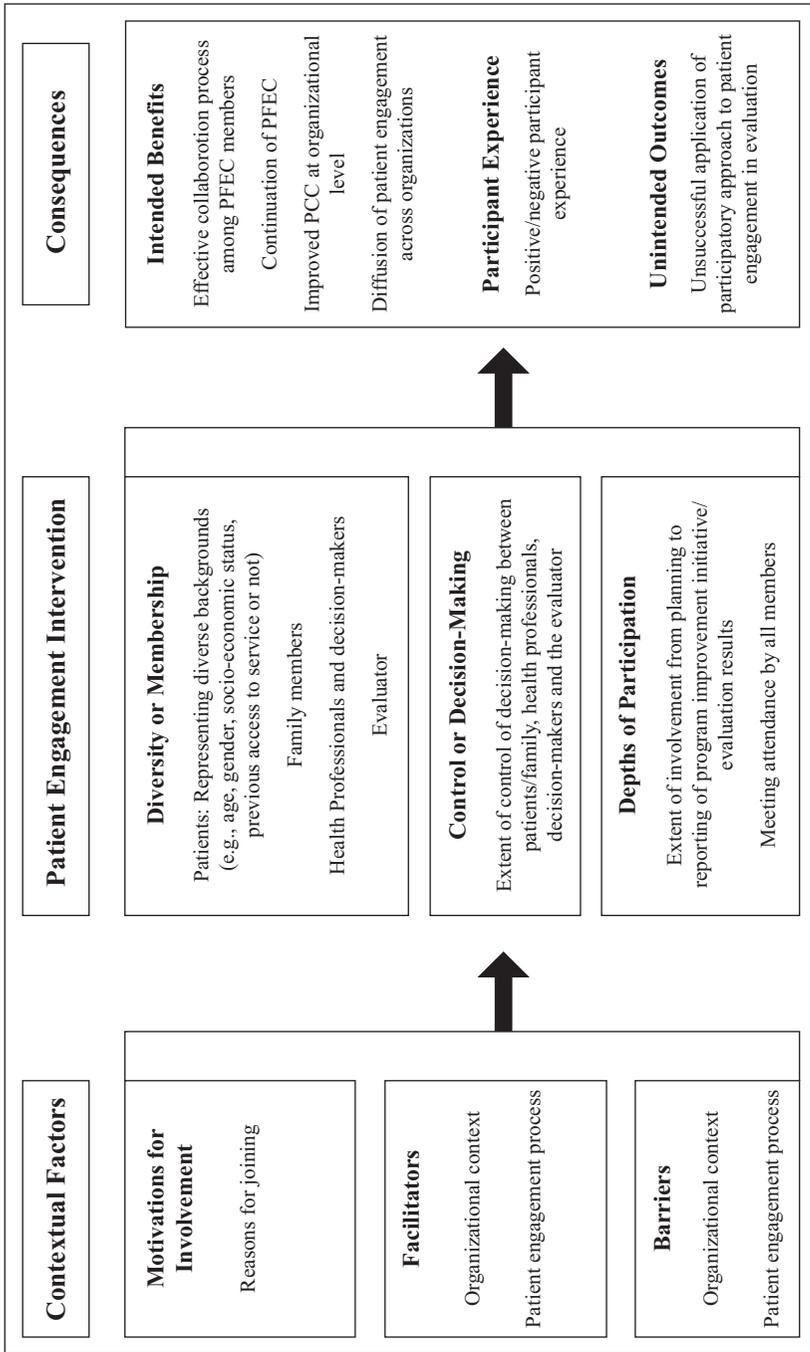
Early deliberations of the PFEC led to a collaborative decision to conduct a needs assessment of the program to identify areas of the PSOP most in need of improvement. Using CAE, the first author worked in collaboration with the PFEC on all phases of the needs assessment over a six-month period. Decisions about the overall areas of focus for the needs assessment, the approach used for working together, how to collect input from the committee members, recommendations to move forward, and reporting methods were made collaboratively. The research reported here occurred in parallel with the evaluation project. All committee members were aware and supportive of participation in the research.<sup>1</sup>

We developed a conceptual framework to inform the study by explicating the key constructs to be studied and the suggested relationships among them (see [Figure 1](#)). The framework is based on patient-centred care (PCC) theory, associated concepts of patient engagement emerging in the literature, and validated process dimensions of collaborative inquiry ([Cousins & Whitmore, 1998](#)). It served as a guide to data collection, analysis, and interpretation, but following [Miles and Huberman \(1994\)](#), our application left open the possibility of identifying and tracking emergent concepts and variables.<sup>2</sup>

Addressed by the framework are antecedent conditions and factors, the nature of collaborative practice (i.e., patient engagement), and the consequences of such practice. The first aspect of the research examined contextual factors, which includes facilitators and barriers affecting the patient and family engagement intervention (e.g., attitudes toward involving patients and family in program improvement activities; representation from diverse patient and family groups in terms of age, gender, and culture). We envisaged these factors to influence and shape the patient and family engagement process, corresponding to the three process dimensions of collaborative inquiry originally set out by [Cousins and Whitmore \(1998\)](#): the extent to which patients, family, and other program community members are in control of technical evaluation decision making, the diversity in stakeholder participation in the inquiry, and the extent to which members engaged with the full range of evaluation tasks and if their involvement changed as the process unfolded. The third panel of the framework lays out the intended consequences of the patient and family engagement intervention (e.g., sustainability of engagement activity, members' experience, level of diffusion of patient and family engagement across the organization). It is important to note that we were also sensitive to the identification of unintended outcomes.

### ***Data collection and analysis process***

Data collection consisted of four phases, which sought to explore changes that occurred over time associated with context, process, and consequences of patient and family engagement. In these phases, data were collected at baseline (i.e., following the orientation meeting), mid-project, end-of-project, and follow-up intervals. The primary sources of data for the first three phases were program documents, participant observation by the first author as PFEC lead, field notes, and multiple interviews with participants. Participant observation was guided by a checklist for



**Figure 1.** Conceptual framework: Contextual factors, intervention, and consequences.

consistency, while the first author recorded reflections about the research questions throughout the process using field notes. In order to minimize researcher bias, an independent interviewer conducted a total of 30 interviews with PFEC participants at baseline (post-orientation meeting), mid-project, and end-of-project intervals. This strategy proved to be quite effective in prior research on participatory evaluation (Robinson & Cousins, 2004). The interviews were guided by a pilot-tested, semi-structured protocol that mapped onto the nature, causes, and consequences of patient and family engagement in the CAE process (i.e., research questions specified above). Audio-recorded interview data were withheld from the researchers by the independent interviewer until the evaluation project had been completed. The data were analyzed by the first author in consultation with the second author to maintain quality assurance. The preliminary results were summarized in a case report, integrated into a presentation and focus-group meeting at the follow-up interval. The purpose of the focus group in this final phase was to validate the preliminary findings and add value to them through associated discussion.

### ***Qualitative analyses***

In keeping with Leshem and Trafford (2007), the conceptual framework offers “a self-audit to ensure cohesion and appropriate conceptualization for research conclusions” (p. 101) and may evolve as the research evolves. We aimed to make the process of data analysis as visible and transparent as possible through continuous self-reflection on the research objectives, conceptualizations, approaches, and decisions made (MacNaughton, 2001; Ortlipp, 2008; Stake, 1995). The findings of this case study contributed to a modest refinement of the conceptual framework and further clarified the concept of patient engagement.

The analyses were conducted by the first author in consultation with the second author for quality assurance. The first author transcribed and entered into NVivo (version 10) all data, including interviews, field notes, and participant observations. Initially, the first author explored the data to gain a general understanding; memos were created as a first step to assist in the development of codes, themes, and a preliminary codebook. The second step involved grouping and attending to all sources of evidence, coding the data by labelling ideas, and developing themes from similar codes to reflect increasingly broader perspectives (Creswell & Plano Clark, 2011; Miles & Huberman, 1994; Yin, 2009). Once a theme was identified, the first author explored and compared whether it emerged across all sources of data. This process ensured that the key emergent themes were supported by more than a single source. Additionally, key themes were further explored to determine if they were specific to particular groups of participants (i.e., staff vs. patient and family). Preliminary results were summarized in a case report and shared with all members of the PFEC. Subsequently, the second author facilitated a focus-group meeting with all members of the committee, which was intended to validate the findings, and to collect new “added value” information that represented the group’s perspective regarding the patient and family engagement process. The independent interviewer assisted with the facilitation and recording of the focus group.

Our longitudinal, qualitative methodology enabled us to explore the continuous engagement process of the needs assessment that involved many cycles of belief development and actions and decisions. It provided a rich means to deepening understanding of the CAE process itself and the consequences of patient and family engagement on participants and the program. We now turn to a thematic summary of the findings.

## THEMATIC ANALYSIS AND INTERPRETATION

As mentioned, the results of the study are summarized in the version of the conceptual framework appearing in [Figure 1](#). A general left-to-right pattern of influence is apparent, but it is important to note that reciprocal effects were evident as well. For example, membership diversity was found to be the result of motivations for participation and various facilitative variables, yet member participation also influenced these conditions.

Below we highlight the relevant themes from the framework that make important contributions to the patient and family engagement literature and the field. This presentation of findings and their interpretation is organized according to contextual factors, the intervention/process, and consequences.

### *Contextual factors*

#### *Facilitators*

Several contextual variables were identified across all three phases of the study that facilitated successful implementation of patient and family engagement: Each of these facilitators varied in terms of intensity of participant endorsement, depending on the phase of the study. Having a designated lead with evaluation skills emerged in all phases and as the most endorsed facilitator in the final stage of the project.

In the extant literature, some researchers indicate that having a dedicated champion and/or committed leadership and building staff capacity to work with patients are important facilitators (e.g., [Baker, Fancott, et al., 2016](#); [Luxford et al., 2011](#)). Our findings build on those of [Luxford et al. \(2011\)](#), particularly that key facilitators to improving PCC are building the capacity of staff in the areas of communication, learning about the values of PCC, and customer service/leadership skills. To elaborate, participants in this study specifically identified evaluation skills as critical to the process. Salient among evaluator skills were leading and facilitating the engagement process; ensuring project goals were developed to reflect the needs of the program and PFEC members; and remaining neutral, thereby allowing a diversity of opinions to be heard. Also identified were asking key questions to stimulate discussion, having strong understanding of participatory approaches to planning and evaluation, and consolidating and disseminating information for discussion. The following comments show how the evaluator was responsive to the exigencies of the group and sensitive to not overburdening members:

We have a limited amount of time to hear everyone's ideas, which is why I suggested giving us "homework" as early as possible, so that we could try and circulate responses well before meeting again, so that we could think about each other's responses.

(Patient or family member)

I guess there's kind of been this tension between us not wanting to burden patients and patients saying, "please burden us." I think that's been handled well too, because [the evaluator has] heard this. So what she does is, she suggests things to be done outside of the sessions, but makes it very clear there's no obligation to do that. So people do what they can, and what they feel that they're able.

(Staff)

Overall, participants viewed the evaluator role as important to the evaluation project and emphasized that it was key for moving the engagement process forward.

Researchers have reported that commitment and staff attitudes toward collaborating with patients and family become increasingly favourable through joint work, and that organizational culture becomes more open to working with patients as a result (Baker, Judd, et al., 2016; Crawford et al., 2002; Luxford et al., 2011; Maher et al., 2017). Our data support these claims, as reflected in one participant's observation:

I think that it speaks to the commitment I have, because I am willing to extend my day. It also speaks to the fact that I think this is a meaningful project. If I didn't think this was important, I'd say, "oh, sorry, I can't participate." To me, this was important so it's worth making that extra effort.

(Staff)

We observed mutual respect to be the most prominent facilitator to patient and family engagement. Interestingly, when participants were probed about the issue, they could not provide clear or definitive answers. Yet some did speculate about what might have contributed to this outcome, as can be seen in the following example:

Not every committee has had that kind of respect actually. There's a strong desire certainly, in the family/patient, and probably with the hospital staff as well, that we want to make it better for the next person. If my volunteer work on this is to make any difference at all, then we have to be patient and listen to the other person and to offer valued legitimate opinions.

(Patient or family member)

From another perspective, staff participants involved in the study are clinicians in the area of psychosocial oncology, which requires health professionals to have strong communication skills (i.e., active listening) and to work within a multidisciplinary team, a pattern that contrasts with many acute care models and aligns with CAE. Further, in this instance, the recruitment process for patient and family members was rigorous and most likely contributed to having patient and family members who were committed to engaging with staff in joint work.

Other participants shared that the orientation *meeting* was critical for setting the tone for the collaborative atmosphere. Specifically, participants identified the importance of being given the time to share their story with other committee members as a critical factor for members to have a better understanding of their motivations for joining the PFEC and what their health-care experience had been like. They also suggested that the approach used by the evaluator to facilitate the collaborative engagement process may have contributed to mutual respect among members. Participants appreciated efforts made to accommodate their needs (e.g., having food/beverages, teleconference to avoid travel) and felt their voices and opinions were valued. Ultimately, no single factor was identified but, as [Shulha et al. \(2016\)](#) propose as one of the principles for guiding CAE, efforts put forth to foster meaningful relationships (e.g., building respect, trust, transparency) all contribute to the successful implementation of a collaborative engagement process.

### *Barriers*

Monitoring and responding to resource availability (i.e., time, budget, and personnel) is one of the principles identified to guide CAE ([Shulha et al., 2016](#)). Our findings add further empirical evidence to its importance: a lack of time and resources emerged as the most significant barrier to successful patient and family engagement. While previous research has identified the importance of organizational support for patient engagement ([Abelson et al., 2015](#); [Baker, Judd et al., 2016](#); [Gagliardi et al., 2008a](#); [Luxford et al., 2011](#); [Maher et al., 2017](#)), our findings extend our understanding of the issue by clarifying the types of support needed. These include protected time from clinical/research/administrative responsibilities for all staff, sufficient budgetary allowance to support administrative costs of the evaluation project (e.g., food/beverages for participants, parking/travel reimbursement), adequate meeting space with teleconference capabilities for out-of-town members, and sufficient project time to collaborate on realistic and sustainable program improvements. Consistent with [Shulha et al.'s \(2016\)](#) assertions, when participants are committed to meaningful engagement and there are process and capacity-building goals, CAE such as patient and family engagement may take more time to be implemented compared to conventional approaches.

The challenge for patients still undergoing treatment and at risk of a change in health status to attend all meetings was a theme identified during the early phases of the project. This theme did not reoccur after Phase I, but some participants did mention that they appreciated not feeling any “pressure or guilt” if they were unable to attend a meeting due to illness or low energy. Living at a distance, especially during the winter months, was also identified as a barrier to participation but having the option of participating remotely when necessary was appreciated.

Scholarship on health care has underlined the importance of shared decision making when collaborating with patients and family members on quality improvement projects, as well as assurance that the views from all stakeholders are heard and respected (e.g., [Baker, Fancott, et al., 2016](#); [Baker, Judd, et al., 2016](#); [Gagliardi et al., 2008a](#)). Participants in our study reported that finding their

voice was challenging at times, especially in the early phase of the project, when some members dominated the conversation and inhibited the ability of others to participate equally. The following observation is illustrative:

I feel like there's not always time to speak because some people really get going and it's very difficult to turn them off for a little bit, because [the evaluator] doesn't want to just cut them off because they're talking about their really personal experiences and even I wouldn't cut them off. But I do get kind of, "Okay, wrap it up!"

(Patient or family member)

Some described these challenges as the "growing pains" of any collaborative work; that is, it takes time for teams or working groups to establish efficient ways of working together, especially when members are new to one another. Our data show that participants accepted the "messiness" of the early stages of the collaborative process and argued that it takes time to establish efficient and effective ways of working as a group. A staff member articulated the challenge this way:

. . . we know that going through treatment and early recovery from treatment, people are fatigued, they're still working out a lot of existential issues around what they've been through, so sometimes to catch people this early is a challenge; . . . however, I think to get the true feedback from patient experience, people have to be fairly close to the experience.

Another observed how the ethos of the group and the challenge changed over time. Once members were more comfortable with one another, focus and staying on task were sometimes difficult to manage:

. . . group cohesion has formed, people are not shy anymore, they're really engaged. . . . So, I think at some point we realized oh my gosh, we have to be careful to control or guide the work we're doing, because we could just talk and talk and talk and it could go on, right?

Overall, participants noted the importance of flexibility within a meeting to create a safe space for all voices to be heard, as well as the understanding that conventional meeting procedures might need to be adjusted for successful collaboration between patients, family members, and staff.

### *Motivations for involvement*

The findings of this study also offer important insights into the motivations driving patients, family members, and health professionals to undertake this type of collaborative quality improvement work. [Shulha et al. \(2016\)](#) and [Ma-her et al. \(2017\)](#) emphasize clarifying the motivation for collaboration (e.g., purpose, information needs, expectations) and what this means in practice. Patient and family participants in our study were highly motivated to participate on the PFEC as a way of "paying it forward" for good care received and/or as a way of improving health services for future patients. The following comment is telling:

I got so much benefit from the services that were offered here, and so I thought there's got to be a way to maybe help others to figure out that these services are available, and that they can really help, even when you don't think you need help.

(Patient or family member)

Staff participants were motivated to challenge their own assumptions and learn from patients and family through the evaluation process as a means to improve services. These observations depart from those reported by [Fudge et al. \(2007\)](#), which focus mainly on meeting personal health-care needs. Examples were largely self-centred, such as interest in meeting others in similar situations, accessing health-/social-care services, and having a say about the services used. In contrast, giving back to the system, learning, and improving health services for others, findings emerging in our study, were comparatively altruistic. Here is an example:

By using their feedback, we would like to improve our services, which would then go to improve the experience and services of many other patients in the future, so it would have major impact potentially . . . at the end of the day, it's all about service delivery and providing excellent patient care.

(Staff)

According to researchers on PE, engagement activities need to have clear goals and be value-based; they need to be engaging to patients and families on issues that are, at the same time, important to them individually and to the organization ([Armstrong et al., 2013](#); [Baker, Fancott, et al., 2016](#); [Maher et al., 2017](#)). Our findings are corroborative. An excerpt from the research journal sheds light on the matter:

I think it was just a very welcoming, comfortable group. We laughed a little bit; it was relaxed to some degree or another, but also people have strong feelings. This is a very significant event that they've experienced in their life . . . That has a lifelong impact, and they feel very strongly about the discussion and felt that they had a lot to offer and wanted to make that contribution.

Engaging patients and family and health professionals early on about the motivations for working collaboratively does not guarantee successful collaboration, but the process of discussing how the collaboration will unfold can help all stakeholders articulate the assumptions and needs that the patient and family evaluation project is intended to address ([Maher et al., 2017](#); [Shulha et al., 2016](#)).

### ***Patient and family engagement intervention process***

An ongoing weakness noted in the patient and family engagement literature is the lack of guidance for the successful operationalization of patient and family engagement in practice. A related challenge is addressing the gap between the intended level of interactive and ongoing involvement of patients and their actual involvement, that is to say, maintaining genuine collaboration as opposed to mere

consultation (Bombard & Baker, 2011; Fudge et al., 2007; Maher et al., 2017; Tedford Gold et al., 2005). Participatory evaluation approaches have been suggested in theory as leverage for successful implementation of patient and family engagement, but to date, in the health-care sector, there has been little evidence to show that such approaches have been successfully used or evaluated (Armstrong et al., 2013; Baker, Judd, et al., 2016; Bate & Robert, 2007; Bombard & Baker, 2011). Our data provide such evidence. As described above, we reflected on the participatory approach used for this study using the process lens (i.e., control diversity, depth of participation) provided by Cousins and Whitmore (1998). These dimensions helped shape the collaborative patient and family engagement process and offered a practical aid or decision points in determining and evaluating the integrity of the patient and family engagement design and process. Our findings support and corroborate Abelson et al.'s (2015) tool for the evaluation of the public and patient and family engagement through the application of the aforementioned CAE dimensions of process. For example, some of the prioritized outcomes for successful engagement proposed by Abelson et al. (2015) include having participants representing a diverse range of views, access to supports to enable genuine participation, and an engagement process that informs planning and decision making, all of which contribute to learning.

Findings related to the diversity of members of the PFEC revealed some interesting ideas around who should be involved in patient and family engagement activities and suggest the development of tactics for recruiting groups that would be more challenging to access (e.g., homeless population, single mothers). The following two perspectives speak to the matter:

From my layman's perspective, I mean, I guess when you look at the facts, you've got male-female, you've got age, disease site, socio-economic situation, like I don't know the answer really . . . but again, I think over time, it'll become more evident who is missing.

(Patient or family member)

There were certain more "vulnerable" groups missing. And I suppose, unfortunately it's the nature of this kind of project that you don't get them as easily . . . but what would you do? How would you get to them? I don't know; maybe you will have to seek them out in a different way.

(Patient or family member)

Although it is by no means easy to do, we are persuaded that efforts need to be made to successfully involve patients and family members who are less accessible using conventional recruitment efforts.

Shulha et al. (2016) claim that successful CAE relies on relationship building. Our results add support, as the successful operationalization of the PFEC was shown to depend on the quality of the relationships that patients, family members, health professionals, and the evaluator are able to develop and sustain. Such requires purposeful and transparent efforts on behalf of all stakeholders to develop trust among members and to foster meaningful working relationships.

As the following comment underscores, the process of developing meaningful working relations is not likely to be an easy one:

Yes, sometimes that process can take a while to get everyone in the same direction; especially when it is a new group of people and everyone is getting to know each other and you are trying to tackle some pretty involved issues in what ultimately is a very short period of time.

(Patient or family member)

Questions surrounding control of decision making in patient and family engagement can be difficult to manage and are often associated with less-than-successful patient and family engagement activities (e.g., [Fudge et al., 2007](#); [Gagliardi et al., 2008a](#); [Luxford et al., 2011](#)). The literature strongly advocates that health organizations build staff capacity to work with patients and help them recognize the value of collaborating with patients and family members ([Baker, Judd, et al., 2016](#); [Fudge et al., 2007](#)). Other key facilitators to successful engagement are preparing patients and family members involved in health service improvement activities for their roles and responsibilities ([Armstrong et al., 2013](#); [Baker, Judd, et al., 2016](#); [Maher et al., 2017](#)) and ensuring they are engaged in issues that are of value to them ([Armstrong et al., 2013](#); [Maher et al., 2017](#)). The following quotations illustrate the importance of member input and the democratic nature of decision making within the group:

We had to quickly pare that down to something more manageable. I think that was totally understandable and I think it was a good decision and I think we are ultimately focusing on the most important issues and the ones we can have ultimate impact. I feel the committee is working towards those goals.

(Patient or family member)

I think the group discussions were the basis [of information for the evaluator to use to summarize to the group]. Summarizing the points, and then presenting them as potential decisions, or suggestions. Most of the time those things were accepted by the group. Sometimes they were slightly tweaked to better represent what we thought that we meant, but I think the group as a whole did the decision, although the actual summarizing of it was done by [the evaluator].

(Patient or family member)

[Baker, Fancott, et al. \(2016\)](#) describe how patients and family members are experts by experience, based on their health-care experiences as users. Our findings are corroborative but add value by nuancing key contributions related to specific stakeholder groups. Here, a former patient reflects on the value of his own experience with services:

What I've seen happen to others around me, I have had quite a wide range in experience with my cancer. I've been intimately involved in surgery, chemotherapy, and radiation, all twice. . . . So I think I have maybe a better idea than a lot of people on the different areas for improvement.

(Patient or family member)

Participants identified that the key contributions of the evaluator were organizing or facilitating the process and having evaluation skill sets:

I would assume that if she's evaluating things, then she would provide a lot of input to the evaluation process and hopefully some sort of recommendations could come out of it. It seems kind of obvious that her role would be very central to the whole thing.

(Patient or family member)

As the participant implies, the evaluator's strong role may have moderated depth of participation, or the extent to which non-evaluator members of the team engaged with technical aspects of the needs assessment. But the non-evaluator stakeholder members made significant contributions to defining and clarifying issues. Staff were seen to provide program and organizational context and reality checks, as well as the ability to effect change. To illustrate:

Staff members can provide more background about what the limitations in the system are, what are their current plans to improve things, what has been tried in the past or we are not going to go down that route because we have tried that before. I think the staff participation is critical.

(Patient or family member)

Patient and family members, on the other hand, contributed most by providing contextual knowledge of lived experience and challenging the status quo. We provide further support to [Armstrong et al. \(2013\)](#), who contend that patients can challenge the status quo or, in their words, function as a "technology of persuasion," challenging assumptions that everything is fine and resolving contestation about whether proposed changes are appropriate.

### **Consequences**

What are the observed effects of patients, family members, and staff collaborating on a quality improvement project, and to what extent did these observed outcomes depend on process dynamics? Despite long-standing calls to learn from practical experience through empirical study (e.g., [Baker, Fancott, et al., 2016](#); [Bombard & Baker, 2011](#); [Fudge et al., 2007](#); [Gagliardi et al., 2008b](#)), this exploratory study represents one of very few prospective intervention case studies examining the intended benefits, unintended outcomes, and participant experiences using a participatory approach.

#### *Intended outcomes*

Our findings reveal that participants involved in this quality improvement project expect that the intended benefits of their involvement will be multifaceted. Identified were reaching decision makers, improving health services, increasing diffusion of patient and family engagement activities across the program/organization, improving access and awareness of services, and following up to

assess the influence of the evaluation project (e.g., informed planning/decision making, improved health services). Following are some exemplary comments that illustrate these expectations:

I was like, “Oh, maybe that’s not, that’s brilliant. Maybe we never thought of that, let’s pursue that.” So, it’s been a nice experience, and I think we all like that we’re all there for that common goal of improving patient experience and patient services. So, we’re all there for the same reason, but we’re coming about it from different angles. So, that’s nice.

(Staff)

It feels a little bit like the information is out there. Are the decision makers going to implement it? I don’t know. Did they hear it? I think they heard what we said, and will it be brought forward. I believe so. Is it going to go anywhere with it? I don’t know.

(Patient or family member)

So at the program level, I think definitely there are, for some components, very easy changes that can be made. But at the broader level, I think certainly the suggestions would be taken much more seriously with the patient inclusion in there.

(Staff)

It is important to recognize that our findings from the interview data about the impact of the CAE process are speculative and perhaps more about what is likely to happen as opposed to direct observations changes that did happen. Still, the results are supportive of [Abelson et al.’s \(2015\)](#) contention that successful public, patient, and family engagement informs planning and decision making; supports ongoing quality engagement in strategic planning, policy, and service delivery; and demonstrates how participants’ input will be used in decision making. During the focus group, staff participants were able to identify some practical outcomes that were influenced by the work conducted by the PFEC. For example, two clinicians provided concrete examples of how they had made changes to their practice based on what they had learned through the engagement process. PSOP staff also shared that they had changed their program signage to ensure it was more visible within the cancer program. The physician on the committee confirmed sharing the PFEC report with the cancer program’s medical advisory committee in hopes of influencing decision makers to support some of the recommendations made by the PFEC. Despite the short duration of this project and the inability to assess long-term practical outcomes, there is some anecdotal evidence of those in the shorter term. Furthermore, based on the focus-group discussions, we are optimistic that the patient and family engagement process will continue to influence practical and transformative outcomes across the cancer program.

### *Unintended outcomes*

Our findings relating to unintended effects of the CAE process were somewhat nuanced and limited. One participant developed her own insights into service provision at the PSOP and realized that she had been unaware of some of the

selection criteria and that she ultimately could have navigated the program much earlier than she did:

Well, at some points it was very hard. I realized, and I told my husband, that according to the criteria of the patient's priority to access for PSOP, I should have been marked as priority number one . . . I was never recognized as one, and instead of being referred to the program immediately and hearing the feedback from the program within the first weeks, I was referred to it 15 months after.

(Patient or family member)

It is difficult to say whether this disturbing knowledge adversely affected her participation in the project or whether it fuelled her desire to assist with efforts to improve services. Given the operation and productivity of the committee, the latter is certainly likely. Another unintended consequence was decidedly positive and reflected on the energizing benefit for a staff person of participating on the PFEC. In her words,

In the hospital you drag yourself from one committee to the next, thinking "ah ... thank goodness that's over, I don't have to worry about it for another month or whatever," but these people were like give us more. [Interviewer: and that surprised you?]. In some ways, yes; that motivation and that energy was actually very good.

(Staff)

Finally, studies examining the participant experience of those involved in an evaluation project involving patient and family have reached mixed conclusions. For example, some report that the engagement process was rewarding and participants appreciated being involved, while others report patient dissatisfaction with the process and lack of interest in being involved in health improvement initiatives (e.g., [Fudge et al., 2007](#); [Gagliardi et al., 2008b](#); [Maher et al., 2017](#)). [Frosch et al. \(2012\)](#) and [Gagliardi et al. \(2008a\)](#) report some reluctance on behalf of some health professionals to support shared decision making with patients. Yet reported participant experiences in this evaluation project involving patient and family were comparatively inspiring: personal reward; enhanced optimism about positive influence on the program and organization; enthusiasm for the project and its potential, including some unintended positive consequences of participation that included closure of the loop on healing, a shift from personal to broader health-care focus, and enhanced learning. These results further support [Armstrong et al.'s \(2013\)](#) findings that making patient and family involvement work well in practice requires a non-hierarchical structure among members, with a strong emphasis on learning from one another. They also highlight the value of CAE as one way to engage patient and family members in collaborative work.

## LIMITATIONS OF THE STUDY

As with any research study, this one has limitations that should be taken into consideration. The unique focus on the out-patient PSOP as the case under study for this

exploratory research has generated findings that are unique to this program and not necessarily applicable to other health-care programs. For example, staff participants by nature of their role within the PSOP have highly developed communication skills and work within a multidisciplinary model, which requires collaboration with other specialties. These skill sets may have contributed to the positive patient and family engagement process and PFEC dynamics and may not necessarily be representative of the collaborative nature of the majority of health professionals.

As a result of this study being constrained by short timelines, we were unable to examine the long-term impacts or outcomes that the evaluation project involving patients and family would have on the program and organization. Some anecdotal evidence was provided with respect to short-term practical outcomes related to the work completed by the PFEC, but long-term outcomes could not be examined.

## IMPLICATIONS FOR RESEARCH AND PRACTICE

Our findings provide a range of insights and ideas about the value of CAE in the context of collaborative health-care practice. We turn now to reflections for ongoing research on evaluation in this context and to practical implications for evaluators' consideration.

### *Research*

The findings of this study suggest several opportunities for further research. While the study provides a first step toward a better understanding of contextual factors (i.e., facilitators, barriers, and motivations for wanting to engage in patient and family engagement activities), it also highlights the possibilities for continued research to shed further light on some of these findings. Given the qualitative nature of this inquiry, with its attention to the rich lived experiences of participants, we are unable to comment on the generalizability of our findings. Yet we believe that the conceptual framework that we developed for this research has been validated and that it offers a coherent starting point for further inquiry.

Despite emerging evidence that suggests patient and family engagement leads to improved PCC and organizational improvements (Baker, 2014), we need to explore and gain a better understanding of evaluation approaches that could contribute to translating patient and family engagement into improved outcomes. We suggest the following research objectives and questions as being of high interest to growing the knowledge base.

- Despite significant effort, the extent to which patients and family have been engaged in health-care quality improvement has been limited mostly to various forms of single time-point consultation, rather than a genuine interactive partnership based on principles of CAE. Of interest would be an examination of the applicability of the *Principles for Guiding CAE*, developed by Shulha et al. (2016), to the development of effective

engagement processes. Such activities have significant potential to leverage evidence-based decision making in the interest of service improvement.

- What are the practical and transformative outcomes of engaging patients and family members in the planning and evaluation process? To what extent do these observed outcomes depend on process dynamics? Researchers should consider field-testing the Public and Patient Engagement Evaluation Tool (Abelson et al., 2019), which would benefit from further refinement based on empirical inquiry.
- The findings of this study enhance our understanding of key contributions that patients, family members, health professionals, and evaluators bring to the patient and family engagement process. Further research is needed to explore key competencies and/or characteristics required by those who lead evaluation projects involving patients, family, and others who may be involved.

### *Practice*

A cultural shift is occurring within the Canadian health-care system, requiring patients to be engaged in health service planning and evaluation. Examples of this shift are patient and family engagement policies being developed across different levels of health care, the creation of patient and family advisories, involvement of patients in the development of clinical guidelines, and patient-oriented research initiatives. This changing context holds important implications and opportunities for evaluation. For patient and family engagement to be accepted and effective, policy makers and organizational decision makers interested in establishing patient and family engagement strategies must be prepared to debate why patient and family engagement is desired and what is hoped to be achieved. They must also embrace evaluation approaches such as CAE that are consistent with the philosophy of PCC, and policy and organizational leaders need to be committed to encouraging health professionals' acceptance of patient and family engagement in planning and evaluation activities. Additionally, policies need to assist and direct health-care organizations to go beyond conventional methods for capturing patient experience and adopt a strategic organizational approach to patient and family engagement.

Finally, if the idea of embracing CAE as an effective mode of inquiry in this domain has merit, it behooves evaluators to consider the prospective application of the evidence-based principles of Cousins (2020) and Shulha et al. (2016) to guide CAE. The present study drew from these principles on a retrospective basis but confirmed them to be relevant and beneficial. Applying the principles from the outset by engaging evaluators and program community members alike holds good promise of fostering productive and beneficial collaborative processes (Cousins, 2020). It would also be worthwhile to capture the challenges and benefits of using the principles through some sort of action research or field trial perspective. That being said, it would be imperative to ensure that program stakeholder perspectives are integral to the inquiry (Cousins, 2020).

## CONCLUSION

Our hope is that the results of this study will contribute to increased successful implementation of patient and family engagement and generate new research activity in the study of patient and family engagement in the planning and evaluation of health services. To date, only a limited amount of empirical research has examined the effects of patient and family engagement, investigated the best approach to engage patients, or systematically evaluated patient and family engagement implementation. To our knowledge, this the only study to examine prospectively the various constructs involved in patient and family engagement using a participatory approach. The use of multiple data-collection methods, particularly the 30 independent interviews at multiple time points during the engagement process, enhances our contextual understanding of key factors affecting the process of engagement through CAE and its consequences for participants. Strengths of this prospective intervention study were that it allowed for examination of participants' experiences through the course of the evaluation project and could identify changes occurring over time.

This study also identified important areas where we believe the evaluation community can play a significant role in continuing to advance the body of knowledge and practice of patient and family engagement. Our intention has been to explicate some options for more collaborative practice and to inform a future research agenda that will add new insights and advance our understanding of patient and family engagement. In the end, our hope is that research on patient and family engagement will help highlight the importance of including patient and family perspectives to create a more responsive health-care system.

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## NOTES

- 1 The research received ethics approval from the University of Ottawa and the participating hospital system.
- 2 Although structurally identical to the preliminary conceptual framework, [Figure 1](#) is a revised version that was enhanced to reflect substantive findings of the study.

## REFERENCES

- Abelson, J., Li, K., Wilson, G., Shields, K., Schneider, C., & Boesveld, S. (2015). Supporting quality public and patient engagement in health system organizations: Development and usability testing of the Public and Patient Engagement Evaluation Tool (PPEET). *Health Expectations*, 19(4), 817–827. <https://doi.org/10.1111/hex.12378>. Medline:26113295

- Abelson, J., Tripp, L., Kandasamy, S., & Burrows, K., on behalf of the PPEET Implementation Study Team. (2019). Supporting the evaluation of public and patient engagement in health system organizations: Results from an implementation research study. *Health Expectations*, 22(5), 1132–1143. <https://doi.org/10.1111/hex.12949>. Medline:31373754
- Armstrong, N., Herbert, G., Aveling, E.-L., Dixon-Woods, M., & Martin, G. (2013). Optimizing patient involvement in quality improvement. *Health Expectations*, 16(3), e36–e47. <https://doi.org/10.1111/hex.12039>. Medline:23374430
- Baker, G. R. (2014). *Evidence boost: A review of research highlighting how patient engagement contributes to improved care*. <http://www.cfhi-fcass.ca/sf-docs/default-source/reports/evidenceboost-rossbaker-peimprovedcare-e.pdf?sfvrsn=6>
- Baker, G. R., & Denis, J. L. (2011). *A comparative study of three transformative health care systems: Lessons for Canada*. <http://www.cfhi-fcass.ca/sf-docs/default-source/commissioned-research-reports/Baker-Denis-EN.pdf?sfvrsn=0>
- Baker, G. R., Fancott, C., Judd, M., & O'Connor, P. (2016). Expanding patient engagement in quality improvement and health system redesign: Three Canadian case studies. *Health-care Management Forum*, 29(5), 176–182. <https://doi.org/10.1177/0840470416645601>. Medline:27576853
- Baker, G. R., Judd, M., Fancott, C., & Maika, C. (2016). Creating “engagement-capable environments” in health care. *Healthcare Quarterly*, 21, 11–34.
- Bate, P., & Robert, G. (2007). *Bringing user experience to health care improvement: The concepts, methods and practices of experience-based design*. Radcliffe.
- Bombard, Y., & Baker, R. G. (2011). Patient engagement: Evidence on successful strategies. Paper presented at the meeting of The Change Foundation, Toronto, ON.
- Cousins, J. (Ed.) (2020). *Collaborative approaches to evaluation*. Sage.
- Cousins, J. B., & Whitmore, E. (1998). Framing participatory evaluation. *New Directions for Evaluation*, 1998(80), 5–23. <http://dx.doi.org/10.1002/ev.1114>
- Cousins, J. B., Whitmore, E., & Shulha, L. M. (2013). Arguments for a common set of principles for collaborative inquiry in evaluation. *American Journal of Evaluation*, 34(1), 7–22.
- Crawford, M. J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., & Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care. *British Medical Journal*, 325(7375), 1–5. <https://doi.org/10.1136/bmj.325.7375.1263>. Medline:12458240
- Creswell, J., & Plano Clark, V. (2011). *Designing and conducting mixed methods research* (2nd ed.). Sage.
- Frosch, D. L., May, S. G., Rendle, K. A. S., Tietbohl, C., & Elwyn, G. (2012). Authoritarian physicians and patients’ fear of being labeled “difficult” among key obstacles to shared decision making. *Health Affairs*, 31(5), 1030–1038. <https://doi.org/10.1377/hlthaff.2011.0576>. Medline:22566443
- Fudge, N., Wolfe, C. D. A., & McKevitt, C. (2007). Assessing the promise of user involvement in health service development: Ethnographic study. *British Medical Journal*, 336(313), 1–8. <https://doi.org/10.1136/bmj.39456.552257.be>. Medline:18230646
- Gagliardi, A. R., Lemieux-Charles, L., Brown, A. D., Sullivan, T., & Goel, V. (2008a). Barriers to patient involvement in health service planning and evaluation: An exploratory

- study. *Patient Education and Counseling*, 70(2), 234–241. <https://doi.org/10.1016/j.pec.2007.09.009>. Medline:18023129
- Gagliardi, A. R., Lemieux-Charles, L., Brown, A. D., Sullivan, T., & Goel, V. (2008b). Stakeholder preferences for cancer care performance indicators. *International Journal of Health Care Quality Assurance*, 21(2), 175–189. <https://doi.org/10.1108/09526860810859030>. Medline:18578202
- Gilbert, N., & Cousins, J. B. (2017). Advancing patient engagement in health service improvement: What can the evaluation community offer? *Canadian Journal of Program Evaluation*, 32(2), 1–20.
- Leshem, S., & Trafford, V. (2007). Overlooking the conceptual framework. *Innovations in Education and Teaching International*, 44(1), 93–105. <https://doi.org/10.1080/14703290601081407>
- Luxford, K., Safran, D. G., & Delbanco, T. (2011). Promoting patient-centered care: A qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *International Journal for Quality in Health Care*, 23(5), 510–515. <https://doi.org/10.1093/intqhc/mzr024>. Medline:21586433
- MacNaughton, G. (2001). Action research. In G. MacNaughton, S. A. Rolfe, & I. Siraj-Blatchford (Eds.), *Doing early childhood research: International perspectives on theory and practice* (pp. 208–223). Allen & Unwin.
- Maher, L. M., Hayward, B., Hayward, P., & Walsh, C. (2017). Increasing patient engagement in healthcare service design: A qualitative evaluation of a co-design programme in New Zealand. *Patient Experience Journal*, 4(1), 22–32. <https://doi.org/10.35680/2372-0247.1149>
- Miles, M. S., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Sage.
- Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *Qualitative Report*, 13(4), 695–705. <https://doi.org/10.46743/2160-3715/2008.1579>
- Robinson, T. T., & Cousins, J. B. (2004). Internal participatory evaluation as an organizational learning system: A longitudinal case study. *Studies in Educational Evaluation*, 30, 1–22. <http://dx.doi.org/10.1111/j.1745-7599.2008.0060.x>
- Shulha, L. M., Whitmore, E., Cousins, J. B., Gilbert, N., & Al Hudib, H. (2016). Introducing evidence-based principles to guide collaborative approaches to evaluation: Results of an empirical process. *American Journal of Evaluation*, 37(2), 193–215.
- Stake, R. (1995). *The art of case study research*. Sage.
- Tedford Gold, S. K., Abelson, J., & Charles, C. A. (2005). From rhetoric to reality: Including patient voices in supportive cancer care planning. *Health Expectations*, 8(3), 195–209. <https://doi.org/10.1111/j.1369-7625.2005.00334.x>. Medline:16098150
- Van De Bovenkamp, H. M., Trappenburg, M. J., & Grit, K. J. (2009). Patient participation in collective healthcare decision making: The Dutch model. *Health Expectations*, 13(1), 73–85. <https://doi.org/10.1111/j.1369-7625.2009.00567.x>. Medline:19719537
- Yin, R. (2009). *Case study research: Design and methods* (3rd ed.). Sage.

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