

Report from the Canadian Association of Psychosocial Oncology Annual Conference

Patient and family advisors

CCO, CCS AND CAPO INTEGRATE PATIENT AND FAMILY ADVISORS

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The role of patient and family advisors (PFAs) in the provision of patient centred care was a central theme at the 2018 Canadian Association of Psychosocial Oncology conference. A breakout seminar chaired by Carole Mayer and Esther Green allowed conference participants to gain insight into the use of PFAs in 3 distinct organizations: Cancer Care Ontario (CCO), the Canadian Cancer Society (CCS), and CAPO.

STUDY SUMMARY: A network of patient advisors at CCO

Moody L, Vanta L, Boric T, et al. System-level patient engagement: past, present and future at Cancer Care Ontario. Presented at CAPO 2018, Abstract S166.1.

CCO is the primary advisor on cancer to the Ontario government. It uses research to inform policy and strategic

planning aimed at improving patient care. CCO recognizes patients' and families' unique experiences within the cancer system and seeks to use their feedback to develop guidelines and programming to improve whole-patient care. To this end, CCO has an extensive network of PFAs acting within various committees and working groups. With the support and input from PFA committees, they have developed a curriculum of patient education materials, improved clinic flow, and informed staff training. CCO has been able to create tangible patient satisfaction improvements due to their emphasis on respectful and meaningful engagement with patients and families. Recently, CCO has endeavoured to have more equitable representation of patients and families by attempting to engage under- and never-represented populations. Their strategy includes an online engagement forum, which allows anonymous participation in discussion topics. This engages participants who could not normally

sit in working groups or who would not be comfortable participating in a structured PFA committee to share their experiences, and enables them to contribute to advancing patient centred care.

STUDY SUMMARY: Patient and family roles at the Canadian Cancer Society

Burnett L. Integrating the community voice into the experience of a cancer charity. Presented at CAPO 2018, Abstract S166.2.

CCS is a community-based, volunteer-run charity that seeks to improve the quality of life of cancer patients and survivors, as well as fund research that will help end cancer. PFAs help CCS achieve their mission by participating in grant committees and as program volunteers. PFAs sit on a Patient Panel that, as part of the CCS grant committee, ensures that research maintains a focus on patient-centred care. Patients and family members also deliver programming as support group facilitators. CCS provides training to empower PFAs within this role as a way to further their aim of developing patient centred programming.

STUDY SUMMARY: Patients included at CAPO and its conference

Schulte F, Pagnutti T, McIver C, Mayer C. Patient and family advisors as members of the CAPO community: Embracing 360 Thinking. Presented at CAPO 2018, Abstract S166.3.

CAPO brings researchers, clinicians and professionals together in pursuit of improving and promoting psychosocial care for patients and families. CAPO introduced 2 PFAs to their Board of Directors in October 2017 to provide strategic advice and guidance to move the association toward its goal of patient-focused care. The 2018 CAPO conference in Toronto invited patient and family members to attend the conference and participate in workshops and breakout sessions. CAPO is looking to improve on its patient and family engagement by using the Patients Included charter to design their 2019 CAPO/ International Psycho-Oncology Society (IPOS) conference.¹ This will allow CAPO to further engage patients and families at all levels of psychosocial care, from research to service delivery.

COMMENTARY: The first day of the 2018 CAPO conference in Toronto included a keynote presentation by a mother of 2 living with Li-Fraumni syndrome. She described her experience within the cancer system and the struggles she faces as she tries to balance living life to the fullest while raising her children and receiving treatment for a third malignancy. She opened up to a room full of researchers and clinicians about her daughter's recent Li-Fraumni syndrome diagnosis and how her family is attempting to navigate their health and wellbeing while living with cancer. Her talk emphasized the struggles that she faces balancing being treated for cancer while still living with cancer, a

theme central to the Whole-Person/Patient-Centred care model featured throughout the conference.

Patient-centred care has been a cornerstone of providing comprehensive cancer care to patients since the Ottawa Charter for Health Promotion, developed by the World Health Organization in 1986.² Central to this charter was the need to create supportive partnerships between patients, families and healthcare providers. PFAs are essential to this partnership and have been engaged by various healthcare and research organizations. The 2018 CAPO conference highlighted the importance of PFAs in providing patient-centred care through keynote speakers, patient participants and a breakout session on PFAs.

Two overarching themes emerged from the breakout session on the role of PFAs, despite the fact that the organizations were at different stages in their engagement with patients. The first was that collaboration with PFAs must work through meaningful partnerships, and the second was that whole-person care can only be achieved if there is patient and family engagement throughout the cancer system.

Early in this session, it was suggested that the term “patient and family partners” would be more appropriate to emphasize the collaboration required for meaningful engagement, instead of the more external contribution implied by the role of “Advisor.” In order to foster a true partnership, CCO promotes a “close-the-loop” policy between PFAs and working groups. PFAs receive feedback on their contributions, which creates a respectful and constructive relationship.

PFAs need to be codesigners at every level of the cancer system. This includes research-question development, funding and knowledge translation, as well as policy development and implementation. CCS exemplifies this whole-system approach through its use of PFAs on their grant advisory committees, PFA-directed program development, and PFA-run peer support groups.

The groups represented in this breakout session have eagerly taken on partnerships with PFAs to improve patient care, but it is important to note that gaps in engagement still exist. For example, as highlighted by CCO, there is currently not an equitable representation of all cancer patients among PFAs. Several groups remain underrepresented as PFAs, while others are simply not represented at all (e.g., LGBTQ [lesbian, gay, bisexual, transgender, questioning/queer], people with disabilities, aboriginal people, poor people). PFA committee meetings often take place in major healthcare centres during the day, which precludes many patients from participating. It is, however, imperative that we continue to seek input from underrepresented populations in order to provide whole-patient care throughout the cancer system. CCO has attempted to bridge this gap through the use of social media, which will provide a platform for many underrepresented patients. CCO's use of online engagement is a positive step towards providing accessible and equitable representation by patients not normally able or willing to participate as PFAs. This will remain an important goal moving forward.

Another gap exists in knowledge translation and participation within the research community. CAPO is striving for inclusion with its goal to achieve a Patient Included Con-

ference designation in 2019.¹ PFAs will be engaged in the design and delivery of the conference, and the conference will be accessible to PFAs through funded attendance and virtual access to sessions and participation in discussion. This initiative will give patients and families access to leading research in the field while providing researchers with patient and family perspectives on that research.

As we move forward in pursuit of whole-patient care, we must continue to engage patients and families through PFA roles and ensure meaningful engagement with healthcare professionals. It is important that the needs of patients and their families are always at the forefront as we continue our work in psychosocial oncology.

References:

1. Patients Included™ Conference Charter v1.0 May 2015. <https://patientsincluded.org/conferences/>. Accessed July 19, 2018.
2. Ottawa charter for health promotion. 1986: *Can J Public Health*. 77(6):425–430. Retrieved from <http://www.jstor.org/stable/41989288>

IN BRIEF

Already known

- Patient and family advisors are essential partners in moving towards patient-centred care.

What these studies showed

- Cancer Care Ontario, the Canadian Cancer Society and the Canadian Association of Psychosocial Oncology are all, at different stages, integrating patient and family advisors into their work.

Next steps

- Ensure that underrepresented populations are included through innovative engagement efforts.
- Provide training to empower patient and family advisors.
- Include patient and family advisors in conference design and facilitate their attendance.