The Patient Safety Education Program™
CANADA

Module 7a: Patients as Partners: Engaging Patients and Families: Patient and Family Centred Care

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Abstract

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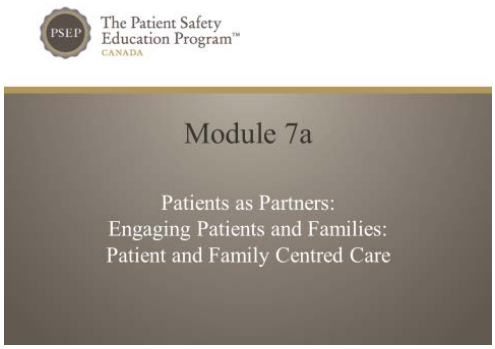

Health care leaders have caught up to patients and families in understanding and truly appreciating how critical it is for care providers and system leaders to effectively engage patients in health care - at an individual and system level. It now seems unimaginable that well intentioned individuals could envision or deliver quality, safe and satisfying care without meaningfully engaging the patient, and those who are significant to the patient, as the ultimate recipient(s) of the care and/or services.

This module provides an overview of Patient and Family Centred Care (PFCC) and meaningful engagement of patients/families in the planning, delivery and evaluation of healthcare.

Keywords

Patient and Family Centred Care; Dignity & Respect; Information Sharing; Participation; Collaboration; Patient Engagement; Patient Partnerships; Partnerships; Patient Safety; Quality of Care; Patient Advisors; Empathy; Communication.

Teaching methods

Interactive lecture; patient story (in person/video); interactive discussions; trigger tape (Cleveland Clinic)

Objectives

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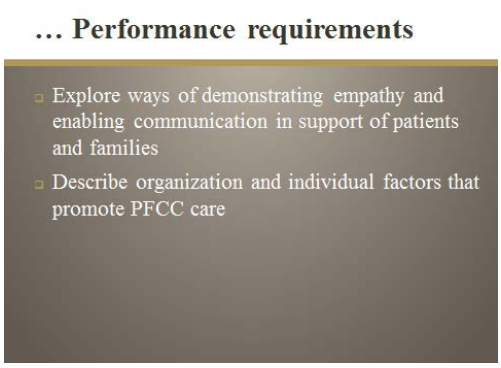

The overarching objective of the module is to create a foundation of understanding of PFCC and engagement, which then can be used for consideration in all aspects of planning and providing safe care and service delivery, and in responding to patient needs at the individual and system level.

Knowledge elements

The knowledge elements include an understanding of:

- patient and family centred care;
- patient engagement;

- benefits and outcomes of patient and family centred care;
- barriers and enablers to patient and family centred care; and
- individual competencies required for of patient and family centred care.

Performance elements

The performance elements include engaging in exercises to:

- describe concepts of patient and family centred care and ways to bring those concepts into practice;
- explore the importance and value of partnering with patients/families;
- explore the barriers and enablers to engaging with patients and families along with means of overcoming them;
- explore ways of demonstrating empathy and enabling communication in support of patients and families; and
- describe organization and individual factors that promote PFCC and partnering with patients/families.

Clinical case on trigger tape

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Trainers are encouraged to search for a trigger tape which preferably is a story told by a patient. Ideally the trigger tape has a patient who has been part of an organization where meaningful partnering with patients/families occurs - and who can relay an account where they experienced the respect and value of engagement. Alternatively, many healthcare organizations will have advisors or volunteers who will tell their story in person, as will representatives from Patients for Patient Safety Canada (PFPSC) www.patientsforpatientsafety.ca and Patients Canada www.patientscanada.ca. The importance of having a patient story is a critical step in modelling within the module the essential value of the patient voice.

Patient and family centred care

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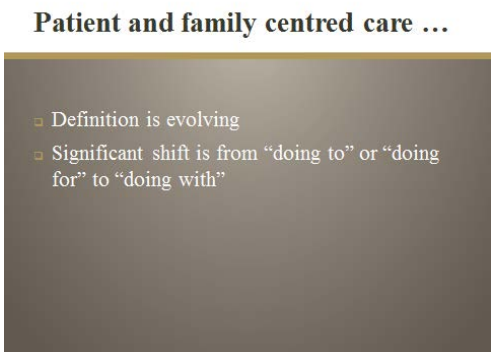

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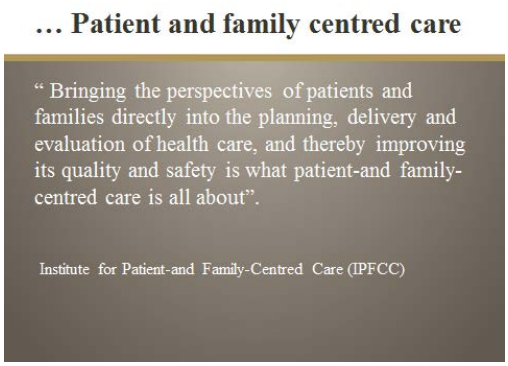

Patient Centred Care, Patient and Family Centred Care, Client Centred Care, Person Centred Care - the nuances in each label may differ but regardless of the specific descriptor, there is no doubt this approach to care, with the emphasis on the role and experience of the recipient of services, is now considered a pillar of a high-performing, high quality health care system. For the purposes of this module, the reference will be to Patient and Family Centred Care. For ease, all care and service providers will generally be referred to as care providers.

The concept of Patient and Family Centred Care (PFCC) is not new, and currently practicing health care professionals may react or take exception to a suggestion of being anything other than patient centred in their approach to care, let alone needing to be more patient and family centred. If however the question of experience and effectiveness with PFCC is put to patients and families, we will hear how individually and collectively we can do better. There is a general sentiment and understanding that everything done by care providers is with expertise and best intention; however, it is also recognized that it is not consistently done in consultation with the patient or with affirmation that the care is aligned to what the patient wants or feels is needed or acceptable.

While the term is widely known to and used by health care practitioners and care providers, there is inconsistency in use of the terminology. This may be partly due to a number of described models of patient centredness, which results in a lack of conceptual

clarity (Scholl I, Zill JM, Harter M, Dirmaier J., 2014). As the emphasis, value proposition and dissemination of information about PFCC grows, the definition evolves, and its meaning today differs substantially from that of past generations. The lexicon that supports PFCC continues to grow as the patient and family voice is increasingly included in care, policy and system design. A significant aspect of the shift over the past years has been from that of "doing to" or doing for" patients, again always with assumption of best intents, interests and skill, to that of "doing with" patients and their defined family.

Definitions of PFCC typically aim to capture what matters to patients and families, and while there may be differences, there are themes that resonate with each.

A widely cited definition comes from the Institute for Patient- and Family-Centred Care (IPFCC, 2011) www.ipfcc.org which has and continues to play a key leading role in advancing the understanding and practice of PFCC. IPFCC is unequivocal in stating that the experience of care, as perceived by the patient and family, is a key factor in health care quality and safety, and that "bringing the perspectives of patients and families directly into the planning, delivery, and evaluation of health care, and thereby improving its quality and safety is what patient and family centred care is all about".

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The core concepts as set out by the IPFCC in 1992 are:

- **Dignity and respect**:
  Health care practitioners listen to and honour patient and family perspectives and choices. Patient and family knowledge, values and beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information sharing**:
  Health care practitioners communicate and share complete and un-biased information with patient and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision making.
- **Participation**:
  Patients and families are encouraged and supported in participating in care and decision-making at the level they choose
- **Collaboration**:
  Patients, families, health care practitioners, and health care leaders collaborate in policy and program developments, implementation, and evaluation; in facility design; and in professional education, as well as in the delivery of care.

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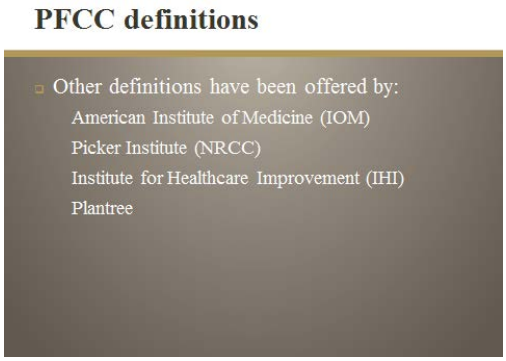

Other descriptions of PFCC reflect similar language and/or themes, with some elaborating more on a specific element(s). As examples:

The American Institute of Medicine (IOM), in its landmark report *Crossing the Quality Chasm: A New Health System for the 21st Century* outlined a vision for a health care system in the 21st century (IOM, 2001). It describes six aims (safety, patient centeredness, effectiveness, efficiency, timeliness and equity) as the basis of a comprehensive quality-oriented health care system) and further describes patient centred care as having six dimensions - respect for patient values, preferences and expressed needs; coordination and integration of care; physical comfort; information, communication and education; emotional support, relieving fear and anxiety; and involvement of family and friends.

The Picker Institute (NRCC) which promotes, provides and facilitates the capture or measurement of the perspective of patients/families through survey, and, thus enabling

the voice of patients to inform quality measurement, improvement and health care redesign, approach, describes patient centred care as including the following principles:

- effective treatment delivered by staff you can trust;
- involvement in decisions and respect for patients' preferences;
- fast access to reliable health care advice;
- clear, comprehensive information and support for self-care;
- physical comfort and a clean, safe environment;
- empathy and emotional support;
- involvement of family and friends; and
- continuity of care and smooth transitions.

(Balik B, Conway J, Zipperer L, Watson J., 2011) (Frampton S, Guastello S, Brady C, Hale M, Horowitz S, Bennett Smith S, Stone S., 2008)

The Institute for Healthcare Improvement cites 5 conditions in support of patient and family centred care:

- Respectful partnership;
- Evidence based care;
- Leadership;
- Hearts and minds; and
- Reliable care.

Planetree is a nonprofit patient centred care organization of hospitals and other health care organizations founded in 1978. Now headquartered in Connecticut in the United States, the organization was founded by Angelica Thieriot in San Francisco after her frustration of impersonal treatment as a patient, and is named after the sycamore, or plane tree, that Hippocrates sat under when he taught medicine. Planetree international hospital membership includes Canadian sites in Calgary and Quebec. Its approach to care includes the following components:

- human interaction;
- family, friends, and social support;
- information and education;
- nutritional and nurturing aspects of food;
- architectural and interior design;
- arts and entertainment;
- spirituality;
- human touch;
- complementary therapies; and
- healthy communities.

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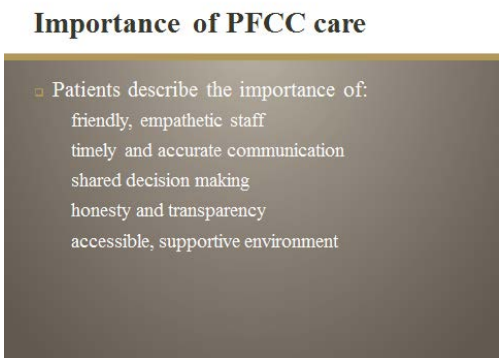

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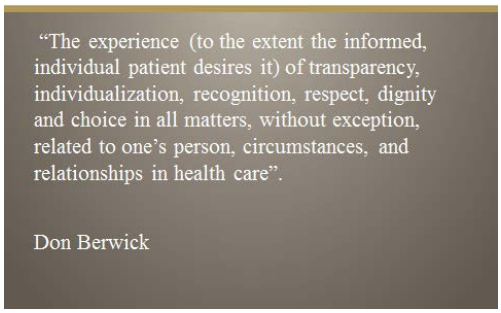

Patients and patient groups also describe what they want in terms of patient and family centred care - typically including but not limited to the wish and expectation of interactions with friendly, empathetic staff; contact with individuals who make themselves known by name and profession/role; honesty and transparency; timely communication and accurate information they can understand; shared decision making; compassionate care and interactions; and an accessible, supportive environment. (Frampton SB, Guastello S, Lepore M., 2013) (Bensing J, Rimondini M, Visser A., 2013).

Don Berwick, in 2009, proposed the following definition: "the experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care". He shares 3 useful maxims: “the needs of the patient come first”; “nothing about me without me” and “every patient is the only patient” (Berwick DM, 2009).

Accepting that as yet there is no unified definition of PFCC, it will be important for every clinician, service provider, volunteer and learner to gain an understanding of the context within their place of employment or service, in terms of how it defines and approaches PFCC. This is essential, for the person who will be directly engaging with patients and indirectly supporting care to be able to actively adopt, support, and influence the improvement of practices, and to align personal behaviours to that goal.

Patient engagement

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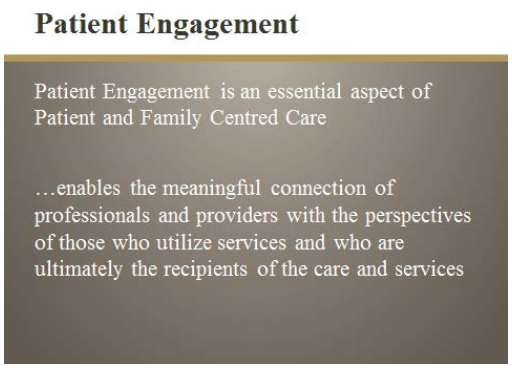

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Patient engagement underpins Patient and Family Centred Care. With patient and family centred care as the goal, patient engagement and partnering with patients are means to that end. (Carman KL et al., 2013). Further, case studies, from international leading organizations, increasingly show that when organizational/system leaders, providers and patients/families work in partnership, there are improved outcomes in so much as the quality and safety of health care rises, costs decrease, and both patient and provider satisfaction increase (All Party Parliamentary Group (APPG) on Global Health, 2014). Patient engagement enables the meaningful connection of professionals and providers with the perspectives of those who utilize services and are the ultimate recipients of the care/services.

Steps taken to promote patient engagement are necessary and ethically justified as they are aligned to the well-established principles associated with patient and family centred care - respect, involvement, participation, collaboration - and because they are associated with better outcomes for patients. A term also arising more recently in literature is "patient activation" which describes the skills and confidence that equip patients to become actively engaged in their health care. Both terms suggest opportunity on the part of both the patient/family and clinicians/service providers to take active, enabling steps.

Patient engagement does carry expectations and obligation for both the patients and providers (healthcare organizations and delivery systems) (Danis M, Solomon M, 2013). Arguably however, the greater onus falls on the care provider to facilitate the process of engagement and relationship building. To do this, providers must be open, welcoming and receptive to having patients/families come to them with ideas, information and questions. Patient'/families do not expect providers to have all the answers; however they do expect to have open dialogue where options can be explored and suggested by the patient/family who have looked for, considered and/or researched options suited to their needs and desires.

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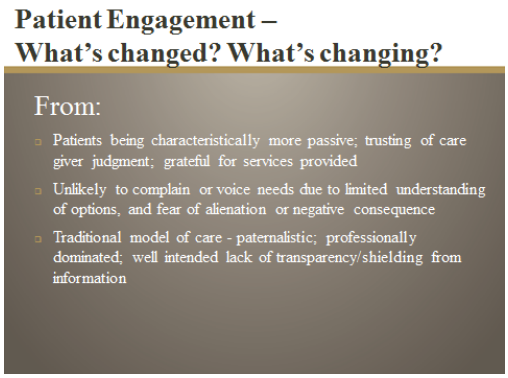

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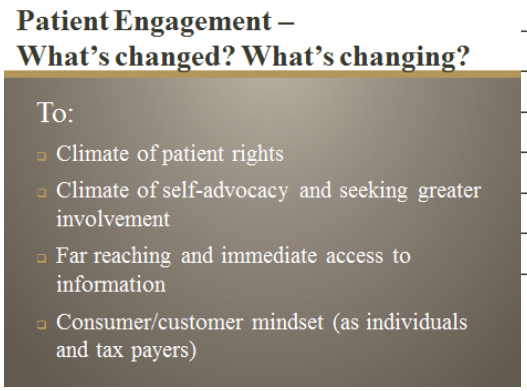

The evolution of patient engagement and authentic partnering with patients/families and providers can be attributed in part to patients and families, as consumers and possibly as taxpayers who support the health care industry, seeking greater involvement. In the past, patients were characteristically more passive, trusting of care giver judgment, grateful for the services provided, and unlikely to complain or voice needs and requests perhaps due

to limited understanding of their condition and options, and also due to fear of alienation or negative consequence. Further the traditional model of care can be described as typically more paternalistic, professionally dominated, quite restrictive and less than transparent, and more about well-intended control in terms of shielding patients from medical discussions and documentation.

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Now however, with generational changes, advanced medicine, ready access to information, and a climate of patient rights and self-advocacy, there is more of a consumer mindset. Patients more predictably are well informed and vocal, are seeking high quality services and experience, and expect access to information that is relevant to them and their care as well as for active involvement in decision making. They expect to be respectfully engaged and that drives the need for collaboration which is the foundation or "bedrock" of PFCC. It dictates need for mutual respect for knowledge, skills and experience; honest and clear communication; understanding and empathy; mutually agreed upon goals; shared planning and decision making; sharing of information; accessibility and responsiveness; joint evaluation of progress; absence of labelling and blaming.

A public engagement model developed by the International Association of Public Participation (IAP2) describes 5 categories to define levels of engagement - inform, consult, involve, collaborate and empower. These are viewed as a spectrum, with "inform" or receiving information being on the more passive end of the spectrum and "empower" being on the active end with final decision making. The impact of the

individual on the decision making process becomes greater on the higher end of the spectrum. Each engagement category has its own strengths and challenges, and most critical is the need for the provider to determine and support the choice of the patient and family in being engaged to the extent they choose.

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The level or scope of engagement also can vary - with the spectrum being an individual care decision level, or at the level of a clinic/inpatient unit/office or organization such as a hospital/care home/community based service provider, or at a health system level (region/province). The level of involvement can also be described as micro, meso or macro as ascribed to organization and/or system. Patients may wish to be actively engaged in decisions about their personal care and wish no further interaction or engagement with the organization or health care system. Others may choose to become involved in sharing their experience/perspectives at an organizational or system level with the goal of making improvements with redesign of structures, policies and processes.

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It is also key for those working within sectors of the health care system to attend to the patient experience and potential impact upon quality and safety at points of transition between sectors, as these reflect the continuum of the patient's care and experience (Raasch J, Peisert K, 2014). Providers must be sensitive to the fact that their engagement is episodic relative to the individual patient's journey with health care needs within and through the health care system.

Sensitivity must be given to the fact that the nature or degree of a patient's involvement may also be influenced by a previous experience - either positive or negative. There is evidence that the desire to prevent repetition of error or future harm is an important variable for patients/families, and often is more important that receiving financial compensation for harm caused in any patient safety incident.

For all of these reasons, clinicians, organizational and system leaders must be mindful of the value of engagement at every level, in every setting and at points of transition along the continuum of care. There will always be value derived from isolated actions to improve patient quality, safety and experience as these will undoubtedly provide localized results. The opportunity to transfer learnings from these localized successes, and the capacity to influence sustained improvements at a system level will come from engagement of patients/families at every level of healthcare planning and delivery.

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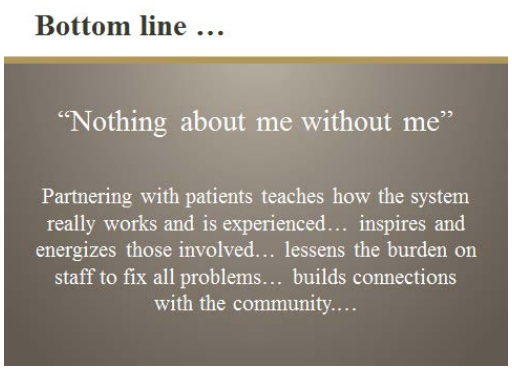

Regardless of the level of involvement (personal, organizational, system), patients/families ought to be engaged and regarded as true and equal partners - not uncompromising dictators or advocates to a specific end. They are experts in themselves, and have been described by many as the greatest previously un-tapped resource within healthcare. When done authentically, partnering with patients and families brings important perspectives about the experience of care and things that are seen differently than what might be seen or understood to be occurring by often busy healthcare/service providers. Partnering with patients teaches how the system really works and is experienced; inspires and energizes those involved; keeps staff grounded in reality; provides timely feedback and ideas; lessens the burdens on staff to fix problems (no one has all the answers!); builds connections with the community; and offers an opportunity for patients and families to give back (IPFCC).

The maxim "nothing about me without me" helps to crystallize the intent of collaboration. "Nothing about me without me" was the concept of a five day global seminar held in Saltzburg in 1998 to develop ideas for improving the quality of healthcare by involving patients. 64 participants from 23 different countries which included health professionals, patient advocates and social scientists created the land of 'PeoplePower' where patients and health professionals would facilitate informed shared decision making. They suggested that a shift from Biomedicine to Infomedicine was the way forward. Shared decision making was viewed as having the potential to improve health outcomes, improve patient satisfaction and to save costs. Evidence shows the advantages for patients living with long-term conditions of working in a partnership with their health professionals. Patients are recognized as experts in their own experience of the condition and their priorities are understood. Conditions that must be in place for shared decision making include ready access to evidence based information; guidance on how to weigh up the pros and cons of different options; and a supportive clinical culture that facilitates patient engagement.

PFCC, Patient Engagement and Patient Safety

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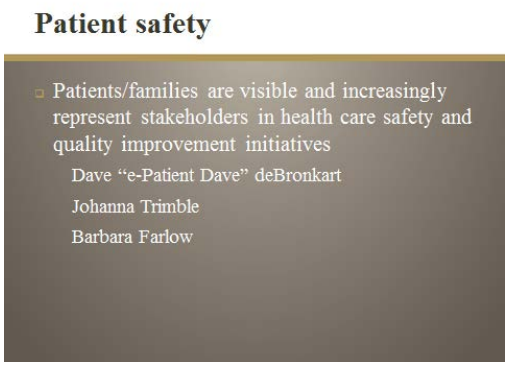

The acceptance of the emphasis on patient centredness and the value proposition for partnering with patients is growing, with greater adoption and transparency in mandates, strategies, and communiques of Ministries of Health, Quality Councils, health and professional organizations across Canada. It is however only in very recent years that patients have been visible and increasingly represented stakeholders in health care safety and quality improvement movements.

The international attention of reducing errors and enhancing patient safety, coupled with the direction of patients and families seeking to be included and being sought for engagement in healthcare improvements bodes well. McDonald, Bryce and Graber (2013), in "The patient is in: patient involvement strategies for diagnostic error mitigation", using the lens of diagnostic error mitigation, look at the merging of the two promising trends of patient engagement and patient safety. They speak of analyzing strategies for patient involvement in the individual's own care, in improving aspects of the healthcare delivery system and in contributing to research and policy development.

There are now many exemplars of how the coupling of these trends is now being realized in health care design and safety improvements within organizations and at a system level (Davis RE et al., 2012) (Mohsin-Shaikh S, Garfield S, Franklin BD, 2014) (Hirschoff, A. Daugherty A, Moore J, editors, 2006) (Clinton L, Jin N, Rosen A, editors, 2012) (Clinton L, Aronson S, Rosen A, Berkow S, editors, 2013).

The Canadian Patient Safety Institute (CPSI) plays an obvious and vital role at the national level and as an international leader in patient safety. The CPSI is a not-for-profit organization that exists to raise awareness and facilitate implementation of ideas and best practices to achieve a transformation to patient safety. It partners with governments, health organizations, leaders, and healthcare providers to use countless evidence based tools and resources. In 2005 the CPSI launched Canadian Patient Safety Week as a national campaign as part of its mandate to build and advance a safer health system, and with the goal of Canadian Patient Safety Week increasing the awareness of patients safety issues and share information about best practices in patient safety. The mantra for the week is "Ask. Talk. Listen.". The 2014 CPSI Forum on Patient Safety and Quality Improvement had an objective of reinforcing the importance of collaboration and partnerships in dealing with patient safety. This was enabled by presentations from leaders from across Canada, and also included issuing of individual and organization Canadian Patient Safety Champion awards for achieving safer care and inspiring stronger partnerships with patients and families. All of this speaks to the CPSI, including its "Ask. Listen.Talk." campaign as proactively modelling and promoting the PFCC expectations of respect, information, participation and collaboration with the goal of safer patient care.

Of great significance, the voices and faces of those who have been harmed in any fashion are much more visible and/or vocal, and there continues to be a shift in emphasis from being primarily concerned with victim support or victim rights to prospective prevention activities.

Patients and their families have become as organized as other stakeholder groups. As example, in Canada, Patients Canada, formerly Patients' Association of Canada, was formed in 2011 and is based in Toronto, Ontario. It is a member organization that brings the voices of patients and caregivers to healthcare in Canada, through the telling of their stories, working to make their healthcare experiences count, and promoting areas and ways that the system is succeeding. Patients Canada, which is patient-led and patient-governed, works with healthcare providers and like-minded organizations to encourage the engagement of patients and caregivers in all aspects of healthcare, the CPSI being one. The areas of work involve using patient experience to improve healthcare, educate for patient partnerships, develop patient leaders and research and publish from the patient perspective. Another example is Patients and Partners/Patient Voices Network (PasP/PVN) based in British Columbia. The PasP/PVN is a not-for -profit Ministry of Health initiative consisting of a community of more than 1500 BC patients, families, caregivers and others who are using their experiences to influence change in BC's health care system at the individual, community, and system level. The network enables

matching of patients with health care providers who want the patient voice as part of their decision making process. The work of the network focuses on making change by enabling quality improvement, public and patient engagement, and through self-management support. As with Patients Canada, PasP/PVN partners with the BC Ministry of Health, First Nations Health Authority, the provincial health and professional organizations.

A patient for Patient Safety Canada (PFPSC) is yet another example of a patient-led program of the CPSI. It serves as a voice of the patient and asserts that there is no greater stakeholder in the effort to improve patient safety than the patients and their families. Guided by the vision of "Every Patient Safe", members initiate and support communication with all decision makers, make presentations, and share stories and the lessons learned so that the voice and presence of the patients influence, lead and collaborate in the achievement of safe care for all. They inspire and impact policy and practices, and promote transparency on patient safety issues.

There are also many individuals who have become singular voices of the "why" and "how'" of patient engagement. Dave deBronkart, also known as "e-Patient Dave" is a leading example. Apart from being an international speaker on the topic, his book "Rx Let Patients Help! - A "patient engagement" handbook - how doctors, nurses, patients and caregivers can partner for better care" speaks to what he describes as the fundamental truths about healthcare, ways to let patients help, and ways for individuals to be e-patients and empowering providers (DeBronkart D, Sands DZ, 2013).

As Canadian patient leaders, Johanna Trimble, a passionate patient advocate and a World Health Organization Patient Safety Champion, who also is on the steering committee of the BC Patient Voices Network and member of Patients for Patient Safety Canada, and Barbara Farlow, a Patients for Patient Safety Canada member, offer strong voice to the impact and experience of patient safety incidents along with the necessity and value of engagement with patients/families.

Leslee Thompson, President and Chief Executive Office at Kingston General Hospital, Ontario is a healthcare professional and organizational leader who shares, at an international level, the story of a hospital turnaround enabled by meaningfully partnering with patients and families, and how this has translated to an improved culture, capacity and outcomes.

It is evident that health care systems and organizations are increasingly embedding the presence and voice of patients and families within the teams or committee structures that design improvements which promote patient safety, minimize risk and support monitoring and education. Patients respond favourably to the respect and collaboration, and clinicians and leaders respond to patients and families who are engaged and share the goals of improved quality and safety. Engaging and partnering with patients/families enables their interests and needs, their responses to the safety improvement recommendations, as well as their recommendations for future action to be captured and

integrated into research activities, policy and legislation development, patient safety education curricula, patient education or patient safety incident reporting systems. This emphasis on PFCC and more active engagement of patients/families, coupled with the changes that have ensued from effective partnering in designing improvements, will be instrumental in addressing what patient safety leaders previously observed as a relative lack of progress in reaching the patient safety incident reduction goals, attributed to limited input from patients and families in ensuring the safety of care (Doherty C, Stavropoulou C., 2012).

Patient engagement - at any level - must be purposeful. The concepts of co-design and shared decision making involve recognizing and acknowledging that a decision is required; knowing and understanding the best available evidence; and incorporating the patient's values and preferences into the decision.

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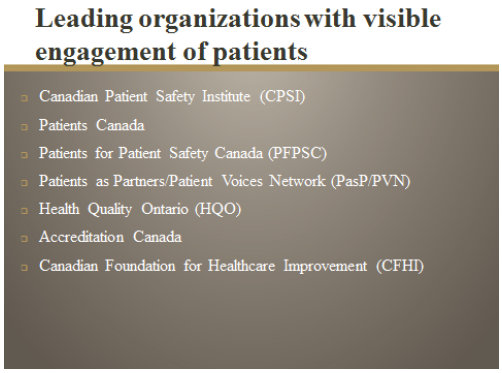

Evidence

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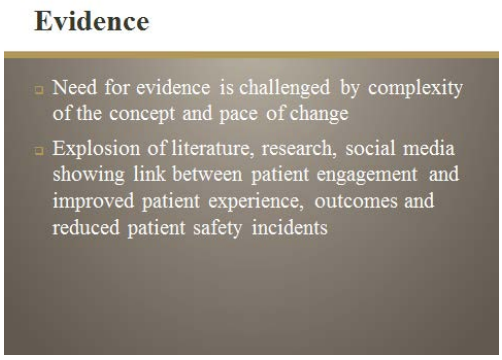

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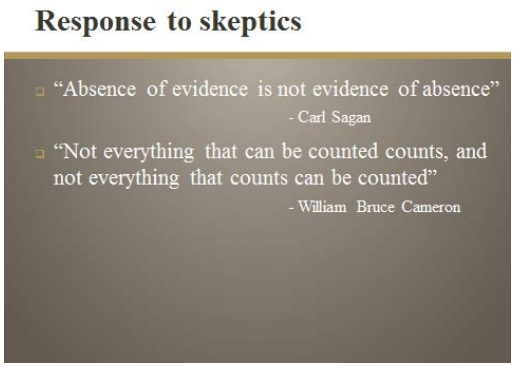

Within a clinical and scientific community, it is understandable to want and seek evidence, or scientific proof, that Patient and Family Centred Care, and the practice of partnering with patients is effective and should be adopted as a leading practice. Some will say at the outset and to the eye of classically trained health care professionals and researchers, that the scientific evidence is light, and there is supporting literature to that effect (Hibbard JH, Greene J, 2013) (Nease RF et al., 2013) (Tzelepis F et al., 2014). As example, a 2014 study of EU hospitals, designed to describe the involvement of patients/representatives in quality management functions, and to assess associations between levels of involvement and the implementation of patient centred care strategies, concluded that "there is insufficient evidence that involving patients and their representatives in Quality Management leads to establishing or implementing strategies and procedures that facilitate care; however, lack of evidence should not be interpreted as evidence of no result." (Groene O et al., 2014). Other assessments of scientific evidence suggest that little research has been performed on health outcomes or interventions aiming to increase patient participation, that the quality of the trials is weak, and that results are non-conclusive. This has been explained in part by the complexity of the concept.

All that said, there is and remains strong opinion - on the part of providers, organizational and system leaders, and most importantly from the perspective of patients, families and others having encounters with the health care system, that there is indeed value and that evidence based medicine will continue to emerge. The grey literature is exploding with support for PFCC and patient engagement, and support advancing practices and approaches that are intuitively sound. While opinions may not be fact and exemplars of success may not be hard evidence, they can all the same be the source of truth and are the basis or hypothesis for research and later evidence. If needed, adages that might help skeptics with keeping an open mind to the concepts and approach are those of Carl Sagan…. "Absence of evidence is not evidence of absence", or of William Bruce Cameron "Not everything that can be counted counts, and not everything that counts can be counted".

Further, the evidence that improving the patient experience and developing partnerships with patients are linked to improved outcomes and reduced adverse events is growing and

is associated with outcomes of better management of complex chronic conditions; reduced anxiety and stress; reduced medication incidents, improved hand hygiene rates, shorter lengths of stay; improved patient satisfaction and experience ratings as examples. There are numerous reports and summaries that speak to national and international initiatives undertaken by organizations or associations that demonstrate improved patient care, processes and outcomes. The Advisory Board Company, through the International Global Centre for Nursing Executives, in several meeting series have shared research, insights and practical, enabling tools (Hirschoff A et al., 2006) (Clinton L, Jin N, Rosen A, editors, 2012) (Clinton L, Aronson S, Rosen A, Berkow S, editors, 2014). Thirteen hospitals/corporation/health regions in Canada were amongst the international advisors to this work. This was similar to the 2008 Patient Centred Care Improvement Guide issues by the Picker Institute in 2008 which expanded on its explanation of patient centred care with very practical examples and tools. Similarly within Canada, as part of one of many educational resources on its website, the Ontario Hospital Association (OHA) in 2013 published "Achieving Patient Experience Excellence in Ontario: An Idea Book", which shared outstanding improvement projects and case studies as illustration of the work unfolding to improve the patient experience. The projects ranged from making cultural shifts to single tactical improvements, and focused on themes of advancing high quality care, caring for at risk patients, engaging patients and families, enhancing communication and improving access.

As well, the number of professional and health care organizations that are leading initiatives which facilitate partnering with patients as a means of improving quality and safety are growing and taking new approaches. As example, in 2014, the Canadian Foundation for Healthcare Improvement (CFHI) created the "Partnering with Patients and Family for Quality Improvement" collaborative to harness the transformational approach of partnering with patients to enable the co-design of improvement initiatives, and lead to improved quality and safety. Twenty-two teams from across Canada, including patients and families were engaged to develop, implement and measure the outcomes of each improvement strategy, and emerging results are positive and offer concrete, innovative ways to meaningfully partner with patients and families.

In keeping with other countries, Canadian health care organizations, professional associations, and government bodies are becoming quite explicit in articulating PFCC and specifically embedding patient engagement language and practices that require partnering with patients as part of strategy, policy, accreditation standards, and legislation. This speaks to the strength of the opinion and emerging evidence for this transformative process. Examples include the Saskatchewan Ministry of Health, Ontario Hospital Association, Accreditation Canada, Canadian Medical Association, Registered Nurses Association of Ontario, Ontario's Excellent Care for All Act (ECFAA 2010), NRC Picker, and Health Quality Ontario. In some instances, there are formal patient advisory councils and in others patients are members of advisory bodies. In all there is demonstration of the value of ensuring the patient voice being at tables that plan,

implement, and evaluate patient programs, and in many instances these groups are becoming resource to other countries.

Evidence that those in health and health quality communities recognize and value the contribution and input of the patient voice in partnership to improve the patient experience and outcomes is also demonstrated with the presentation of recognition awards. The Canadian College of Health Leaders "Quality of Life" award to two patient leaders, Donna Davis and Carol Kushner, Co-Chairs of Patients for Patient Safety Canada is the first time one of the college awards was given to "lay" people. In March 2015, The Change Foundation honoured Ontario's "20 Faces of Change", many patients or family members, as leaders in patient engagement and family focused change in the provinces health care system.

In addition to the information and position statements available on the websites of organizations, there are countless social media sites specifically dedicated to or including trending discussions about patient and family centred, patient experience, partnering with patients, and enabling skills. Commentaries are offered by patients/families, clinicians, educators, organizational leaders, as examples: Patient Experience Champions; Patient Experience Canada; The Patient Experience; The Beryl Institute - Improving the Patient Experience; Patient Education and the Patient Experience; National Patient Safety Foundation; Patients for Patient Safety Canada; Healthcare Executive Network.

The Joint Commission in 2008 correctly pointed out that "the elevation of the patient to partner is not a ceremonial title bestowed for a "feel good" moment, but has significant implications for the quality and safety of patient care." The IHI, similarly in 2011 noted that while patient and family experience may have previously been viewed as a "nice to have", it is now built into performance agreements in a fashion similar to the long accepted clinical quality, safety and financial measures (Balik B et al., 2011). Many provincial ministries are following suit, and the federal government is looking at ways to support this transformative innovation.

There is no disputing the need to advance the research agenda and to build the scientific evidence about PFCC, partnering with patients/families and the impact on safety, quality and satisfaction. There is also recognition of the rich opportunity to engage patients in formulating and affecting the research agenda. Current studies highlight many opportunities, with themes such as the gap between the expressed wish of care providers and patients to have a higher level of patient involvement, and the interventions that are needed for either or both to bridge the gap between desired and actual involvement. Within the United States, the Patient Centred Outcomes Research Institute was created in response to a mandate to conduct comparative effectiveness research in clinical care to inform decision making (Frank L, 2013) (Abma TA, 2009). It set a national agenda for patient centred outcomes research, the agenda for funding priorities, and communication and dissemination of evidence with the goal of increasing the rate of implementation into policy. Similarly in Canada, The Canadian Institutes of Health Research (CIHR) has set a Strategy for Patient Oriented Research. Both the US and Canadian agendas speak to and

model the importance of patient engagement. Academic hospitals, research institutes and associated councils, such as the Council of Academic Hospitals of Ontario (CAHO) similarly focus on establishing patient centred research priorities and plans.

Benefits and outcomes

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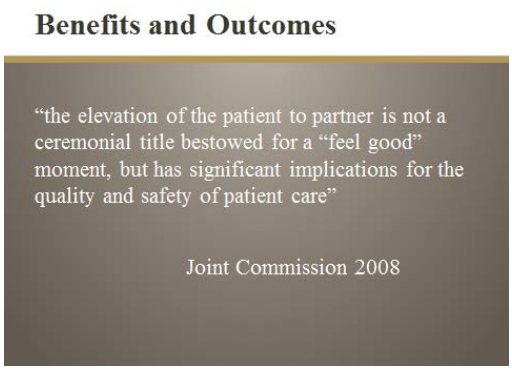

Regardless of role or setting, be it patient/family member, care/service provider, administrator, policy maker, in community, hospital, academia or government, it is increasingly easy to see and hear about the benefits of PFCC and partnering with patients, in terms of culture, quality, safety, experience and operational efficiencies. Appropriately, it is also increasingly difficult to ignore them.

With a mindset of PFCC and an approach of engaging patients/families at the point of care/service delivery and/or as part of teams that co-design organizational and process improvements, organizations are realizing the benefits. These include enhanced operational efficiencies and improved outcomes (reduced lengths of stay, improved care coordination, improved discharge planning); appropriate resource utilization (reduced readmissions or revisits to emergency departments, improved product selection, reduced costs through operational efficiencies, reduced medico-legal costs, improved overall financial performance); improved quality and safety outcomes (reduction in patient safety incidents such as falls, medication incidents; increased hand hygiene; decreased infections, increased patient/family satisfaction) and improved work environment (improved staff retention and engagement results; improved organizational culture).

Many of the improved patient safety and quality outcomes are the result of policy and process improvements made to improve the patient experience. Increasingly these process and policy redesigns are being done with the input of patients and families and with patients/families as part of the improvement teams. As limited and far from inclusive examples - replacement of limited visiting hours with open family presence policies; use of two way communication boards (bedside whiteboards) to enable communication between patient/family members and the clinical team; hourly rounding; bedside handover reports; family presence during rounds; patient personalization posters; patient led feedback forums and high impact storytelling; including patient/family perspective in harmful event analysis and disclosure; experience shadowing (staff shadow patients during most common off ward procedures. These process improvements will create opportunities to improve the understanding of the patient needs and perspectives, and typically will improve caregiver empathy and compassion, and potentially minimize risk of error or further error.

PFCC is not just a token or nice thing to do. It is a transformative model of care that is necessary to safety/quality frameworks at every level -personal, organizational and system.

Barriers and enablers

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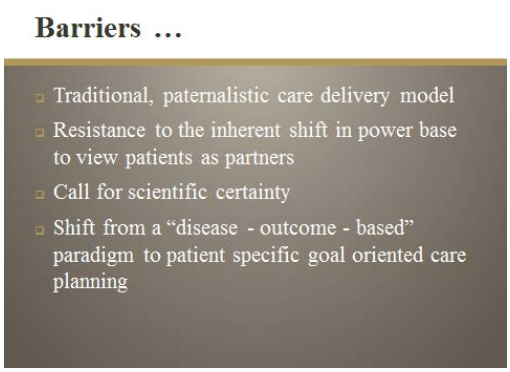

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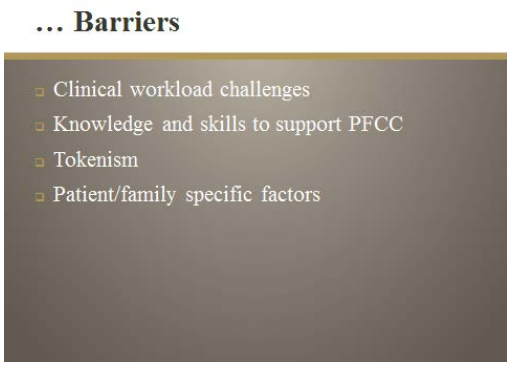

Barriers often present most notably in the face of significant change, and what might be viewed as a barrier to one will be seen as an opportunity to another. The reasons to do or not to do something differently can be countless and may include culture, attitude, knowledge, skill, funding, time, physical limitations, technology...the list can be endless. Without question, if change is desired and to become effected and sustained, the barriers must be understood and addressed, and enablers must be reliable and sustained.

Again without being all inclusive, a few of the predictable barriers or impediments that may present in fulfilling a PFCC and patient engagement mission can be described briefly below.

- The traditional paternalistic care delivery model, with an inherent knowledge and strong sense of responsibility or desire to treat/therapeutically intervene, is in conflict with the emphasis on patient self-determination and participation in care and decision making. While often, and even unfairly, ascribed more to physicians, this paternalism is not exclusive to any category of health care professional and care providers. Involvement of patients and families can be seen as an additive burden to workflow with risk of patients becoming overly demanding, unrealistic and uncompromising. This can be compounded by perceptions and concern with ownership of patient care and information, and the patient's ability to understand and meaningfully participate.
- Depending on current practice, PFCC and engagement dictates a shift in power base to view patients as partners instead of visitors to office, clinic or admission to hospital for professional/provider expertise and services. This can be a radical, unfamiliar, disruptive, and uncomfortable shift in control and power from the hands that provide care/services to those who receive them. There will be real or perceived competing roles for control over the patient's health. Essential is the understanding that PFCC and partnering with patients need not be confrontational and is not an abdication of responsibility. It is not an absolute transfer of accountability for decision making from provider to patient - and instead a more flexible interaction with support for shared decision making. While health care providers are the respected expert medical advisors, patients/families must be respected as the experts about themselves/loved ones, and who will ultimately drive their needs, plans, goals and experience, and have the most at stake.
- As already mentioned, the call for scientific certainty, and the need for confidence and comfort that understandably comes with evidence based medicine can limit the will, timing and readiness for adoption of PFCC practices. The "disease-outcome-based" paradigm, with focus on the disease and priority given to optimal disease management according to guidelines and populations goals, can impede a personalized patient specific "goal oriented" care plan, aligned to the person, their life, their health problem and what that individual patient wants.
- The current healthcare environment is demanding more clinical productivity while affording less time and resource. This is often associated with workload

challenges arising from larger practices/assignments or more patients/clinical volumes per provider. These conditions can be perceived as directly opposed or conflicting with an approach that appears to require more time. What must be considered in addressing this barrier are the inefficiencies and risks that can be avoided in partnering with the patient/family. There are lots of adages to speak to this..."the hurrier we go, the behinder we get"; "a stitch in time..."; "penny wise but pound foolish"; etc.

- Knowledge and skills are essential and any gaps create risk of different or unrealistic expectations (Wittenberg-Lyles E, 2013).
- Organizational factors or process inefficiencies that result in interruptions/interference with work flow.
- Tokenism or merely having patients/family members present at the table. Partnering with patients is a conscious decision to ensure presence and seek/incorporate their input into planning and decision making at the individual or system level.
- Factors directly associated with the patient/family such as lack of assertiveness, health literacy, current emotional state and concurrent illnesses, which may be compounded by provider insensitivity to these issues or needs (Hamann J et al., 2012) (Balogh EP et al., 2011).

The nature of the barrier will determine how is must be addressed. Work system issues, such as policies, standardized processes or programs; environmental/structural issues (space/technology) are bigger than individuals and must be communicated and addressed at an organizational level. That said, patients and families will not always have an appreciation of reason or context for those barriers - they do however experience the impact.

To best realize PFCC and effectively partner with patients/families, the concepts of PFCC are woven into the practice and behaviour of each individual. Further they are supported within a work environment and system that demands and embeds PFCC and partnering with patients into every aspect of its infrastructure. As providers of care and service, individuals working in health care will be best positioned to support PFCC, and partner with patients to enable quality and safety if they have an understanding of factors that support PFCC, and commit to supporting their implementation and ideally the continued evolution of best practices.

Themes present in the literature suggest organizations that succeed in fostering PFCC have gone beyond using traditional or mainstream frameworks for quality improvement, and have adopted a strategic organizational approach to patient focus.

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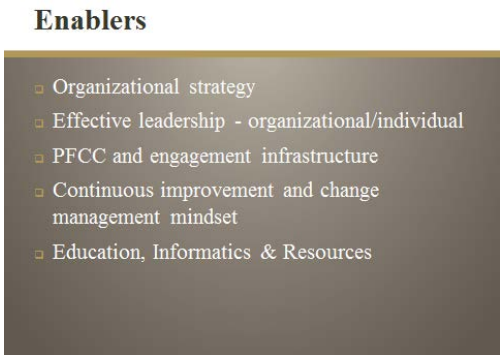

Conditions described as benefitting a strategic organizational approach consist of, and are not limited to the approaches described below.

- Organizational Strategy - reflecting a strong internal and external motivation to change with an authentic commitment to PFCC and partnering with patients. The strategy will include the elements of clear and internally consistent organizational mission, vision, values and priorities committed to PGCC and be supported with action plans and mandatory agreements aligned to the organization's strategy.
- Effective leadership - including Board and Senior Executive, and positional leaders/individuals with technical, professional expertise and creative skills (Taylor J, Rutherford P, 2010).
- Robust organizational capacity - enabled by frameworks for patient centred services; safety and quality of services; and interprofessional collaborative practice or a framework that interlinks all (Brewer ML, Jones S, 2013).
- Educational supports and processes - enabling orientation, education and ongoing learning about PFCC as a central competency with supportive competencies such as communication skills. Patients and families are involved in both the design and the delivery of the education. Face to face educational methods are used for delivering key elements of the curriculum and simulation is used as a method of education, assessment of adoption of practice and ongoing learning (Frankel RM et al., 2011).
- PFFC and Engagement infrastructure (Taloney L, Flores G, 2013) - including staff/organizational champions for PFCC who have positional accountability for embedding PFCC throughout the organizations and who lend passion, expertise and uncompromising focus; Patient and Family Advisors/Champions who become active members, typically on a voluntary basis, who share the patient presence, voice and perspective throughout the organization on design teams (facility design, continuous improvement), standing committees, board structures, interview panels; Patient and Family Advisory Councils which are typically well defined groups of patients/family members and staff who meet on a regular basis to ensure patient experiences, points of view and recommendations are identified

and shared with the organization with a view to improving quality, safety and satisfaction.

- Continuous Improvement mindset - ensuring the organization's culture is strongly supported by performance improvement, organizational learning and effective change management including celebration of successes.
- Performance Monitoring and management - including clear accountability for (possibly aligned to incentives) and sustained focus on measurement and continuous feedback of staff satisfaction, measurement and feedback of patient experiences, clinical and professional development and patient and staff satisfaction.
- Informatics - including electronic health records and navigation tools that minimize duplication and ensure ready access to accurate information.
- Resources - including adequate resources such as space/equipment, staffing models and care delivery designs for care delivery.

While challenging to find an organization that meet all conditions, those leading in PFCC are apt to have or be implementing many. Attendees are encouraged to reflect upon and share understanding of their work environments, and are encouraged to explore further upon return to their work setting.

Individual competencies

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Health care is one of the most intimate services provided or received. Whereas the provider is typically involved by choice in a clinical or service role with a specific and necessary expertise, the patient is typically involved less by choice, more by need/crisis, and is in a very vulnerable capacity. The provider ought to be sensitive to the potential or reality of the power differential and dynamic that exists between care/service providers and care/service recipients.

Patient and family centred care and the capacity for providers and patients/families to partner will be influenced not only by the provider's grounding in the foundational concepts, but also by the nature of the interpersonal relationship that is established between the patient/family and care/service provider. Studies exploring patient and

family views on communication generally suggest that patients want sensitive, caring clinicians who provide information that they need, when they need it, in a way they can understand; who listen and respond to questions and concerns, and who attempt to understand the patient's experience. Effective information exchange and a positive interpersonal relationship are of fundamental importance to patients and families (Mazor KM, et al., 2013).

Attitude and interpersonal skills are the underpinnings of a healthy effective relationship. Empathy and communication skills are among the necessary attitudes and skills often referenced in writing and through the accounts of patients and providers. If authentic and aligned to a philosophy of patient and family centred care, they are ought to be a reliable means of ensuring that patients/families are actively engaged in their care planning, decision making and evaluation of course of care and experience at the level they choose and are comfortable with.

Literature shows a positive association between physician communication behaviours and positive outcomes, such as patient recall, patient understanding and patient adherence to therapy. Communication skills are regarded as a dimension of clinical competency, and best practice communication involves fostering a relationship; gathering information; providing information; making decisions; responding to emotions (King A, Hoppe RB, 2013) (Bombeke K, 2012).

There are many tools available and a wealth of perspectives on how to empathize and communicate with patients and families. Neither may come naturally and therefore there is incredible value to ongoing education about both. While much of the theory available and tips offered seem to be common sense, most acknowledge that they are not necessarily common practice.

Empathy

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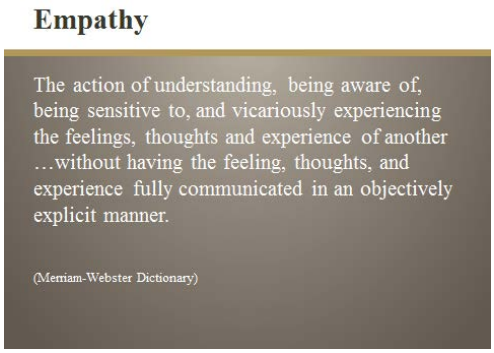

- Actively listening
  - allow ample time for questions
  - don't monopolize the conversation
- Acknowledging what you have heard
- Responding to any questions

Slide 33

A video by the Cleveland Clinic Empathy series is Available on YouTube at the following link: https://www.youtube.com/watch?v=cDDWvj_q-o8.

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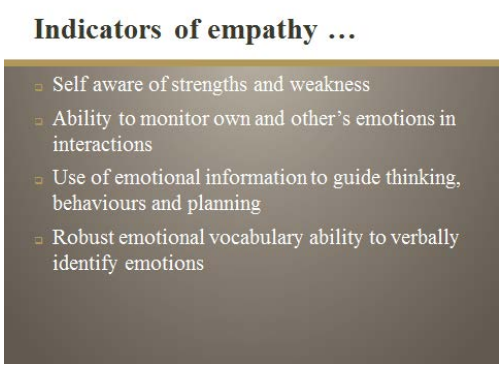

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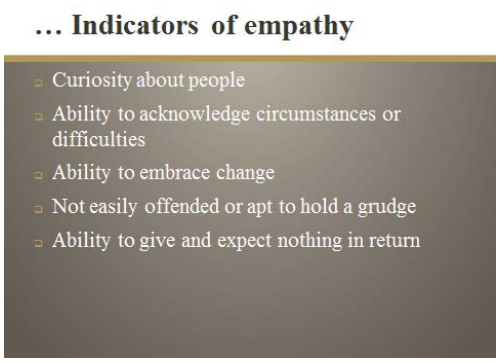

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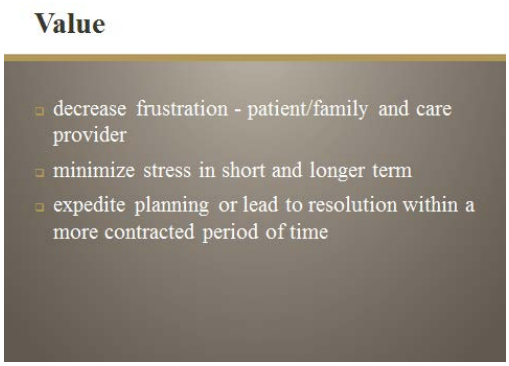

Empathy is the action of understanding, being aware of, being sensitive to, and vicariously experiencing the feelings, thoughts and experience of another of either the past or present without having the feeling, thoughts, and experience fully communicated in an objectively explicit manner (Webster). It has also been described as the capacity to understand what another person is experiencing from within the other person's frame of reference, i.e. the capacity to place oneself in another's shoes; the psychological identification with or vicarious experiencing of the feelings, thoughts, or attitudes of another; or the identification of the emotion the other person is feeling and being able to articulate it. The Cleveland Clinic describes empathy as the human connection in health care, and has a wonderful video series that illustrates the power of empathy.

Studies have shown that providers miss a significant proportion (70-90%) of opportunities to express empathy in the face of patients expressing strong negative emotions (Hsu I et al., 2012). These can be instances of ignoring and dismissing emotion while moving first (or only) to eliciting further information or problem solving.

Empathy must be recognized and valued as a powerful tool in any personal or business relationship - and most definitely in healthcare (Jones LM, Huggins TJ, 2014) (Lelorain S et al., 2012) (Warmington S, 2012). Most people appreciate it when another person understands their position without judgement. It does not replace the need for further gathering of information and problem solving, but it can enhance the nature and effectiveness of the ongoing interaction. Empathy is strongly associated with negotiated

treatment plans, treatment adoption, increased satisfaction, and reduced anxiety/distress (Abbott Moore L, 2010) (Angood P et al., 2010).

Those with empathy demonstrate a deeper level of understanding of the person which is more likely to lead to more compassion and kindness, along with more sincere engagement and personalized service. The patient is more a person than a number, visit, room number or disease label. If a provider is able to identify and relate to the emotion and experience of the patient, they are better positioned to help them work through a situation or need, particularly for those patients/families who may not be able to self-identify or declare their thoughts and feelings. This is why having presentations made by patients and families (patient accounts), or using posters that depict the patients or using statistics that put things in the context of people affected (absolute number of patients who acquire infection while in hospital in place of or in addition to nosocomial infection rates), are so effective in enabling staff to envision the person and patient impact.

It is key for the provider to be able to remain self-aware and monitor their own and others' emotions in the interactions, and to optimize use of emotional information to guide thinking, behaviours and planning. This will call upon many of the aforementioned communication skills in verbally identifying emotions, acknowledging difficulties, validating thoughts and feelings. The process again can help both patient/family and providers by decreasing frustration, minimizing stress in the short and longer term, lead to resolution all within a more contracted period of time.

Those with empathy can be described as having a high emotional intelligence (EI), and EI is described as being associated with how we manage behaviour, navigate social complexities, and make decisions to have positive results. Indicators of higher EI have been described as robust emotional vocabulary; curiosity about people; ability to embrace change; self-awareness of strengths and weaknesses; good judge of character; not easily offended or apt to hold grudge; able to give and expect nothing in return.

Communication

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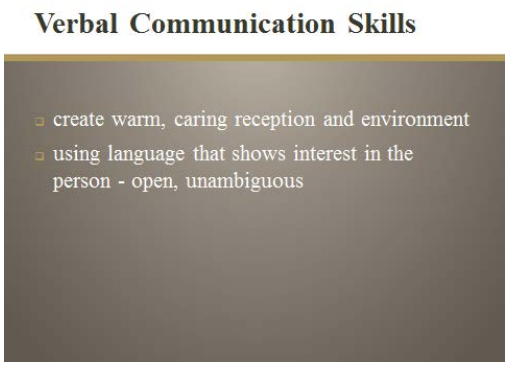

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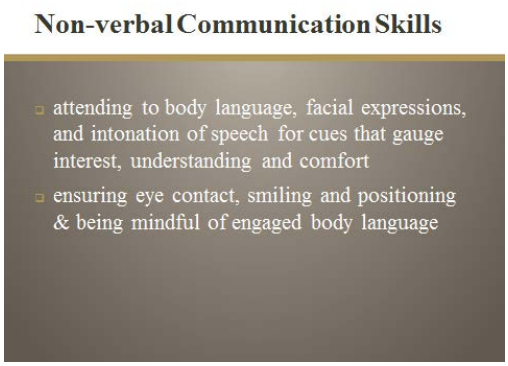

Most health care professionals implicitly or explicitly assume that they use communication techniques that support patient centred care and shared decision making. The use however may not be consistently experienced or affirmed by patients/families or colleagues. Communication skills are learned and should be mastered through practice and ongoing assessment.

There are many useful communication tools and guides available that include approaches and rationale. There is however always need to ensure that communication is customized to individual patients and families and assessed as meeting their needs.

The practitioner needs to focus on improved patient centred communication and risk communication skills. Most literature on communication emphasizes verbal (what is conveyed with words) and nonverbal (what is expressed with body, face and intonation) communication as well as active listening.

Verbal communication involves creating a welcoming, warm, caring reception and environment; using language that shows an interest in the person; being open, unambiguous with presentation of information to a level of understanding of the patient (with consideration of culture, education). It includes an overt validation or acceptance of what the patient/family says or does as an expression of thoughts and feeling in that particular circumstance at that particular time. It does not mean there is necessarily agreement or acceptance of unsafe behaviours, only acknowledgement that the concerns and feelings are important, have been heard and taken seriously, even in the presence of disagreement. Validation should be individualized.

Non-verbal communication entails attending to the patient's body language, facial expressions, and intonation of speech for cues that gauge interest, understanding and comfort. It also involves self behaviours such as ensuring eye contact, smiling, positioning and being mindful of engaged body language.

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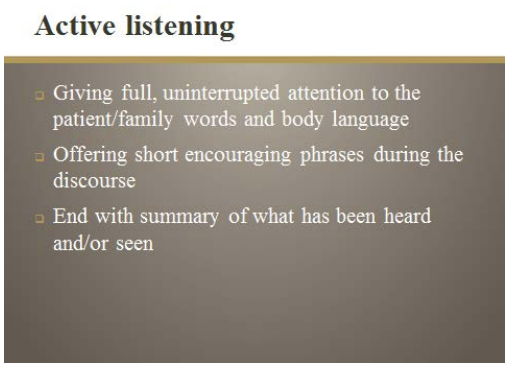
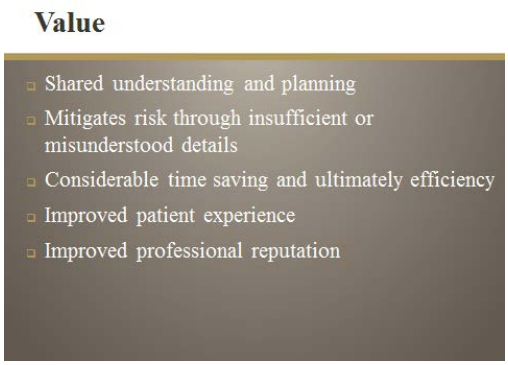


Slide 41



Active listening involves giving full, undivided and uninterrupted attention to the patient's/family's words and presence for messages and nonverbal cues. It includes validation of what is being heard and seen with open body language, non-verbal cues or short encouraging phrases during the discourse and ends with a summary of what has

been heard and/or seen. It is mutually beneficial to patient/family and provider. To the patient it conveys interest, respect and demonstrates good manners.

For the provider, it enables timely and accurate capture of information that helps with better understanding and determination of the patient's circumstance, needs, and/or emotions, and thus better informs options to support their care and better respond to their needs and experience. There can be an improved outcome of shared understanding and planning, with mitigation of risk through insufficient or misunderstood details - all with the additional benefit of considerable saving of time for everyone. To those with competing priorities or inclined to multitasking, it might feel that time spent in this way is an unaffordable luxury; however, it is more apt to save time and resource and result in improved patient experience and professional reputation.

Slide 42

One example of a communication program comes from the Cleveland Clinic. With its guiding principle of "Patients First", the Cleveland Clinic has developed the H.E.A.R.T. program, adopted by many organizations in the United States and more recently in Canada. It consists of educational resources that have demonstrated results of more compassionate, caring and courteous communication not only with patients and families but also with colleagues. It highlights that while the specific clinical setting might be familiar and comfortable to the provider, it can be depersonalizing and overwhelming to the patient and family. Moments and interactions will be highly memorable and with impact. Skills increase the likelihood of those interactions and impacts being positive and effective.

The program "START with H.E.A.R.T." describes nine expected service behaviours:

- acknowledge the person;
- offer to help;
- introduce self and role;
- use preferred name;
- clearly communicate expectations;
- offer to resolve concern or forward to someone who will take accountability;
- use active listening;
- communicate/convey empathy; and
- use common courtesy.

These behaviours are captured and easily remembered with the acronym "START".

- Smile and greet warmly;
- Tell your name, role and what to expect;
- Active listening and assist;
- Rapport and relationship building; and
- Thank the person.

Additionally, the Cleveland Clinic program "Respond with H.E.A.R.T." is designed to increase awareness of the impact of every interaction, every day, with every individual, and create mindfulness that the role each of us plays with experience and satisfaction is greater than the task associated with our role. The acronym H.E.A.R.T. stands for Hear, Empathize, Apologize, Respond, Thank and guides words and actions that elicit understanding of the patient/family experience and enable a constructive response for "making right what went wrong". Each H.E.A.R.T. program goes into rich detail of why each behaviour is important - in terms of creating a safe and caring environment; establishing a respectful and professional rapport at a personal level; building trust; being proactive in understanding; promoting safety and reducing risk; acknowledging and addressing anxieties and emotions; empathizing with the patient/family and empowering them.

The Studer Group is another organization that works with healthcare organizations in the US, Canada, Australia and beyond, to achieve cultural transformation to deliver and sustain exceptional improvement and performance in clinical outcomes and financial results. They too have described and teach fundamentals of patient communication which can be used in patient and family encounters to anticipate, meet and exceed expectations and reduce anxiety. The Five Fundamentals of Service - AIDET - include Acknowledge; Introduce; Duration; Explain; Thank You. With this communication approach, each step conveys to the patient that they are important, in good hands, respected and appreciated, all with the objectives of increasing safety while establishing a respectful relationship.

Although communication is two way, there is understandably greater onus on providers to enable patients with information seeking and question asking, and to take personal

accountability for having flexible and adaptive clinical, patient centred and risk communication skills. Providers need to be thinking of and showing ways for the patients to know the value that is placed on them being actively engaged. Further providers need to enable the patient in being comfortable and confident with information seeking and question asking. A communication intervention - DECIDE - is designed and targeted as a patient education tool, to enable communication and help patients learn to engage in discussion, ask questions and participate in decision about their health care. It is an educational strategy that teaches patients to ask questions, and in doing so improves patient engagement, activation and self-management. DECIDE is an acronym for:

- Decide the problem;
- Explore the questions;
- Closed or open ended questions;
- Identify the who, why, or how of the problem;
- Direct questions to your health care professional; and
- Enjoy as shared solution).

It is an approach that can be facilitated by the health care professional.

The IPFCC has a checklist that enables clinical/service provider self-reflection into attitude and skill with patient/family interactions and communication.

- Do I believe that patients and family members bring unique perspectives and expertise to the clinical relationship?
- Do I encourage patients and families to speak freely?
- Do I listen respectfully to the opinions of patients and family members (and others)?
- Do I encourage patients and family members to participate in decision making about their care?
- Do I encourage patients and family members to be active partners in assuring the safety and quality of their own care? How?

As a care provider, when engaging with the patient/family, you can be engaging by doing those actions listed below.

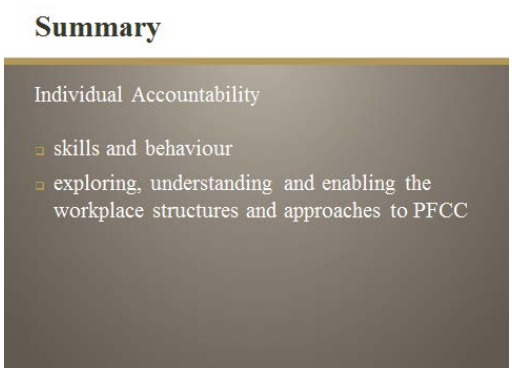
- Be welcoming of the patient and family and convey that you are glad to see them and have time for them (you might not feel this way);
- Say something relevant to suggest you actually remember who they are and don't get this wrong;
- Ask how they are feeling since the last appointment and what brings them to see you - remember it and circle back to ensure it is covered off before the end of the appointment;
- Solicit the patient ideas as to the cause of their complaints and what they would like you to do for them;

- Listen to what they say without interruption - ask clarifying questions, show an interest - patients need to be invited to speak up;
- Share what you recommend and explain why - ask if it is okay and if not, why not;
- Pay attention to patient initiated cues (sighs, uncharacteristic behaviours, description of crises) - they are calls for help;
- Express empathy and support to patients;
- Find out what their health goals are and what steps they believe they can take to achieve them; and
- Ask for suggestions of how you and your team can support their long terms goals.

Individual care providers ought to explore if there is a communication approach that is particularly favoured or promoted within their work setting, and how to avail themselves of educational supports.

Summary

Slide 43



Every individual working in health care, whether directly or indirectly contributes in some fashion to the safety, quality, and satisfaction of the experience of each patient. PFCC is an approach to health care that is now shaping policies, programs, facility design and day to day interactions among patient and families, physicians, nurses and other health care and service providers. Staff across all disciplines and job categories in all care environments have the opportunity to advance the practices and support for PFCC and in doing so be proactive with safeguarding patient care and quality. In the event of unintended incidents, the relationship that has been established will support ongoing discussion and a constructive response.

Potential pitfalls

Slide 44

PFCC is not a passing fancy or craze. PFCC practices are being adopted within organizations and health care systems, and new leading practices are evolving at a rapid pace. "Nothing about me without me" must be now viewed as the gold standard of care.

To say that patient engagement and partnering with patients is complex is an understatement. There are however many exemplars of how it can be achieved with great success and positive outcomes. Each care/service provider must challenge themselves to assess and better their individual practices - with a goal of patient quality, safety and satisfaction as well as for professional competency and satisfaction. Patients should be invited to participate at the beginning of any material/resource development. This will ensure the patient perspective is captured.

Pearls

Slide 45

Success with PFCC and partnering with patients is and will be subject to the quality of leadership - leaders by position and each individual's leadership by behaviour. Leadership in PFCC is about individual mindset, competencies and behaviours. This leadership must be present at every level of the organization and in each interaction from the first encounter with patients and families. How effectively it gets done, will be influenced by the capacity, skills and extent to which individuals understand the core principles and

adopt practices that reflect those concepts - respect, information, participation and collaboration (if using IPFCC). Each participant has the opportunity to continue to advance this transformation in health care. Ultimately, the Golden Rule “Do unto others as you would have done to you" exemplifies what PFCC and partnering with patients can and should be.

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Module 7a Trainer's Notes

Principal message

The single most important message for the audience is that patients (and their defined family) are essential partners in healthcare. Patient and Family Centred Care (PFCC) ensures that the perspectives of patients and families are brought directly into the planning, delivery and evaluation of health care thereby improving the quality and safety for the patient, and typically for the provider as well. Every care provider/system leader has an invaluable and essential role in enabling the partnership with patients/families to ensure that the perspectives of those who are the ultimate recipients of care or users of services are part of the design of that care/service.

Module overview

This message is enabled through understanding of the core concepts of PFCC as well as the barriers, enablers and core competencies associated with patient engagement and partnership.

Attendees will be piqued and encouraged to investigate the infrastructures and processes within their work environments that support PFCC and patient/family engagement and to adopt practices that model and support meaningful partnerships with patients/families in the planning, delivery, evaluation of patient care.

Preparing for a presentation

1. Assess the needs of your audience

Choose from the material provided in the module according to the needs of your expected participants. It is better for participants to come away with a few new pieces of information, well learned, than to come away with a deluge of information from which they can remember little or nothing.

2. Presentation timing

The suggested timing for each part of this module is:

Introduction	2-3 minutes
Trigger tape & discussion	5-7 minutes
Presentation	30 minutes
Debrief about teaching methods	5 minutes
Summary	2-3 minutes

Post-test & Evaluation	5 minutes
Total	49-53 minutes

3. Number of slides: 45

4. Preparing your presentation

The text in the module was not designed to be used as a prepared speech. Instead, the text provides material you may want to use. The slides have been designed to trigger your presentation. Although the slides closely follow the text of the module, they do not contain all of the content. Their use presumes that you have mastered the content.

You may want to make notes on the slide summary pages to help you prepare your talk in more detail and provide you with notes to follow during your presentation.

Remember that you can adjust the slides to suit your presentation content, your style, and to make it feel fully familiar and your own.

Practice your presentation using the slides you have chosen, and speaking to yourself in the kind of language you expect to use, until it is smooth and interesting and takes the right amount of time. The most accomplished presenters and teachers still practice prior to a presentation; don't miss this step.

5. Preparing a handout for participants

The module text and slides in the **Participant's Handbook** were designed to be reproduced and provided to participants as a handout. Take the portion you need; they can be used in their entirety, module by module, or for just one specific topic. Please include the following in each set of handouts:

- **PSEP – Canada Front Cover Page**;
- **PSEP – Canada Acknowledgment Pages** (to acknowledge the source of the material);
- **PSEP – Canada Table of Contents** (to give each participant an overview of the PSEP – Canada Curriculum so they know where their topic fits in the larger scheme of patient safety);
- slides for **your topic**; and
- appendix material as relevant.

6. Equipment needs

- Screen, computer and projector
- Flipchart or whiteboard and markers for recording discussion points

Test your equipment beforehand to ensure that it works.

Review your video segments to assess which trigger videos or portions you would like to use.

Have a back-up plan so that if there is any equipment failure you can move without panic to your back-up plan. For instance, have in mind that:

- If the video fails, you can read the vignette of the trigger tape story;
- If the slides cannot be shown, you can refer to the hand out slides; and
- If markers are not available, you can have participants list items on their hand outs that you would have written up for all to see.

Making the presentation

1. Introduce yourself

If you have not already done so, introduce yourself. Include your name, title, and the organization(s) you work for. Briefly describe your professional experience related to the information you will be presenting.

2. Introduce the topic

Show the title slide for the module. To establish the context for the session, make a few broad statements about the importance of topic as a patient safety matter. Tell participants the format and time you will take to present the session. Identify the teaching styles that you intend to use.

3. Review the session objectives

Show the slide with the session objectives listed. Read each objective and indicate those that you are planning to emphasize.

4. Show the trigger tape

After reviewing the objectives for the session, show a trigger tape. The trigger tape should engage the audience and provide appropriate context for the session. The trigger tape does not need to demonstrate an ideal interaction, but to “trigger” discussion.

Trigger tape content

Keep in mind that the facilitator may choose to use any one of a number of trigger tapes. As stated in the module the trigger tape should be a story told by a patient. Ideally the trigger tape has a patient who has been part of an organization where meaningful partnering with patients/families occurs - and who can relay an account where they experienced the respect and value of engagement

A teachable moment: discussion after the trigger tape

After the trigger tape, ask the participants for their comments about the issues and the interaction they have just seen. To affirm what they contribute, consider recording the important points on a flipchart or overhead projector.

If the discussion is slow to start, you may want to ask more direct questions, like:

- Think of a time when a patient taught you something, reminded you of something or showed you something important you didn't know. What can we learn from that experience that will help us make it happen more often?
- Think of a time when you and a patient or family member accomplished something big working together that you couldn't have done on your own. What were the key ingredients of success?
- Think of a time when you, a family member or friend were a patient. What opportunities did you have to partner? What opportunities would you like to have had?

Use the discussion to set the stage for the material to follow. Do not let the discussion focus on a critique of the technical quality of the video. If the participants do not like something that was said or done in the video, acknowledge that there is always room for improvement and ask them how they would do it themselves.

Setting limits to discussion time

It is usually best to limit discussion of the video to no more than five minutes, then move on to the presentation. To help move on if the discussion is very engaged, try saying something like:

- let's hear two last points before we move on, and
- now that you have raised many of the tough questions, let's see how many practical answers we can find.

For the more advanced facilitator who is very confident of both the patient safety material and his or her pedagogic skills, it is possible to use the trigger tape as a form of case-based teaching and to facilitate the discussion to draw out the teaching points of the module. The hazard of this approach is that the discussion will not yield the desired teaching points. Feel free to return to the slides if this happens. If this approach is used, it is essential to write up the points on a flip chart as they arise, to fill in any gaps and to summarize at the end. Again, use this method with caution and only if you are really ready.

5. Present the material

Recommended style: interactive lecture and patient story

An interactive lecture will permit you to engage your audience, yet cover your chosen material within the time. As well, a patient story either in person or video is critical to emphasize the importance of Patient and Family Centred Care.

6. Key take-home points

1. Patient and Family Centred Care (PFCC) is not a fad or passing fancy;
2. PFCC and engagement is a “disruptive healthcare innovation”;
3. PFCC and engagement leads to improved culture, quality and safety and outcomes; and
4. “Do to others as you have done to you … or yours”.

7. Summarize the discussion

Briefly, review each part of the presentation. Recap two or three of the most important points that were discussed.

8. Debrief about the teaching method

Tell the group that it is time to consider the teaching method used, how it worked and what its limitations were. Ask them what other methods might work, and what methods would work best *for the topic* in their home institutions. Ask them to consider what method would work best *for themselves as facilitators* and for their *target audience*.