

Patient and Family Advisory Councils: Engaging Patients in how Care is
Designed, Delivered and Experienced: A Literature Review

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Abstract

In order for healthcare to be truly patient-centered patients and families must be involved in the planning and evaluation of health services. Yet the question remains-- how to effectively engage patients and families in how care is designed, delivered and experienced. Many organizations are suggesting the development of Patient and Family Advisory Councils (PFACs) as an effective engagement strategy. My goal was to identify key practices required to develop and sustain effective PFACs, as well as determine potential patient, staff and organization outcomes of PFACs. I conducted a literature review, searching three electronic databases for articles or studies about PFACs published in English from 2007-2014 in adult acute care hospitals or cancer centres. Sixty-seven articles were initially identified through electronic searching, eight met the inclusion and exclusion criteria and were analyzed along with two other reports. Six unique essential practices for an effective PFAC were noted across the literature: advancement of the culture of patient- centered care (PCC) within the organization, strategic recruitment of PFAC members, skilled chair/co-chair, well run meetings, presence of a feedback loop, and senior leadership support. Improved patient, staff and organization outcomes such as increased patient satisfaction, increased sensitivity toward the patient experience, extensive and sustained change, decreased length of stay and an improved patient experience were anecdotally noted within organizations with PFACs. However, because of the integrated nature of PFACs within an organization, where PFACs are positioned as part of a much larger team, as well as the lack of patient engagement measures, a direct relationship between PFACs and improved outcomes could not be found. Well-functioning PFACs positioned as respected partners in an organization are starting to contribute to improved outcomes but more research evidence is needed to support PFACs as an effective patient engagement strategy.

Keywords: Patient and Family Advisory Council; Patient-and Family- Centered Care; Patient and Family Engagement.

“We the patients along with our families are the ‘Face of Cancer’. We experience the drugs running through our bodies; have had the surgeries and the radiation; experienced the side effects...dealt with it all. We have a story to tell and share. If you think of this partnership for just one moment-with the people who have the knowledge, research and training plus the patients and their families who have experienced or are experiencing the cancer journey- the care can only get better and better. This is our hope and this is our passion.”

(Patient advisor, Cancer Care Ontario, 2012)

Desiring to partner with patients to improve health services, many governments and healthcare organizations have been looking for ways to successfully redesign health services to shift from “doing for” to “doing with” the patients that they serve. Patients are no longer “complying” or “adhering” to medical or nursing directives but are partnering with their care provider to make decisions that are best for them (Pelletier & Stichler, 2014). Over the past decade the call for increased patient and family engagement and patient-and family-centered care has driven healthcare leaders internationally to critically reflect and initiate change in the delivery of the healthcare services they provide (Haycock & Wahl, 2013). Striving to establish a culture of patient-and family-centered care, quality healthcare agencies and regulatory bodies are advocating that patients and families must be provided with engagement opportunities to influence the organization through the designing, delivering, and evaluation of programs and services (Gagliardi, Lemieux-Charles, Brown, Sullivan & Goel, 2008; Haycock & Wahl, 2013). Canadian healthcare agencies such as the Canadian Foundation for Healthcare Improvement (CFHI), the Change Foundation, the Canadian Partnership Against Cancer (CPAC) and Cancer Care Ontario (CCO) have been developing an array of guidelines and initiatives that promote an

improved patient experience through patient and family engagement opportunities. In 2010, with a desire to join the movement in putting patients first, The Excellent Care for All Act (ECFAA) became law in Ontario. One mandatory requirement addressed in this legislation is that healthcare organizations establish a patient relations process to address and improve the patient experience (ECFAA, 2010). One model that has been proposed as an effective strategy to facilitate patient and family engagement is the implementation of a Patient and Family Advisory Council hereafter referred to as PFAC (CCO, 2013; CFHI, 2013). The model itself is not new as pediatric and mental healthcare centres across the United States and more recently Canada have a history of engaging patients and families through the use of PFACs. Yet the question of effectiveness remains controversial among some healthcare organizations and clinicians who query whether PFACs are an effective patient engagement strategy. Do they result in improved patient outcomes, processes of care, and health services outcomes (Haycock & Wahl, 2013)? The purpose of this project is to review the literature in order to respond to this question, are Patient and Family Advisory Councils effective in fostering patient engagement in healthcare organizations? Specifically, I am interested in the foundational elements required to develop an effective PFAC, and how a PFAC relates to improved patient, staff and organizational outcomes. The project objectives are:

1. To complete a review of the literature to explore how organizations have engaged patients and families in advisory councils.
2. To determine if the implementation of a Patient and Family Advisory Council leads to improved patient, staff and organizational outcomes.
3. To compile a list of foundational elements required to develop an effective Patient and Family Advisory Council.

To begin I explored the concepts of patient-centered care and patient engagement as precursors to the evolution of the Patient and Family Advisory Council model. Initially I chose an integrative literature review method to explore the literature on the experience and findings of organizations with Patient and Family Advisory Councils. After reviewing the literature found through my search I realized that the bulk of information was not research based and I would not be able to present a diverse perspective including a variety of empirical research and non-research. In consultation with a librarian, I repeated my search but these efforts did not produce any additional articles to be included. Although disappointed, I recognized that while this topic does not lend itself to experimental designs, there is some evidence in the literature (albeit non-research) that speaks to my question. Recognizing that the available literature does not lend itself to an integrative review as outlined by Whittmore and Knafl (2005) I transitioned to conduct a modified literature review of evidence addressing PFACs. In order to proceed in a systematic way, and to build on what I had already completed, I modified the steps provided by Whittmore and Knafl as a guide in reviewing the literature on PFACs

The Theory of Integral Nursing, by Barbara Dossey (2008) was chosen to help guide this project. This integral lens supports the understanding of personal experiences as well as the behavior of healthcare providers that are often rooted in the systems and cultures where patients receive their care (Dossey, 2008). In addition, using an integral lens helps value and appreciate multiple perspectives (Dossey, 2008) which is much needed when working with a PFAC that includes both patients and families as well as healthcare providers and administrators. This integral worldview acknowledges the four perspectives of reality- the “I” or individual interior (subjective, personal), the “It” or individual exterior (objective, behavioral), the “We” or collective interior (intersubjective, cultural), and the “Its” collective exterior (interobjective,

systems/structures). This comprehensive structure provides a way to organize the multiple perspectives of the human experience that are intricately linked and bound to each other (Dossey, 2008). Recognizing that no individual or group can determine reality or have all the answers for an optimal patient experience, it is essential when partnering with patients, families and interdisciplinary teams, that an integral perspective or world view is sought. This integral lens values and appreciates the multiple phenomena that contribute to the experience of those utilizing our healthcare system today.

Background

‘Patient engagement’ and ‘patient-centered care’ have become buzzwords among healthcare professionals and the public. Recently the integrated nature of partnerships between patients, families and healthcare providers has started to influence the definitions of these closely related concepts which will be discussed in detail later. Similarly, many of the definitions that have been proposed reflect the values and attributes of each other; interestingly some of the recent literature is starting to view the two terms of ‘patient-centered care’ and ‘patient engagement’ as interchangeable (Pelletier & Stichler, 2014). Evidence related to both these terms continues to support the importance of involving patients and family members in their individual care, and how care is organized, developed and delivered (Haycock & Wahl, 2013; National Patient Safety Foundation, 2014; White, 2012). Professional organizations along with government agencies are advocating for healthcare settings where cultures of patient- centered care are considered the standard and where patient and family engagement is viewed as essential to achieving quality outcomes (Pelletier & Stichler, 2014). Both individually and collectively these agencies are extending a call to action for all healthcare organizations to engage and partner with their patients and families in how care is designed, delivered and experienced.

Patient and Family Centered Care

Patient-and family-centered care is not new to nursing. From the days of Florence Nightingale, nurses have been identifying systems in need of improvement and have strived to work with patients to provide better options to meet individual patient needs (Newhauser, 2003). Partnering with the patient as an individual with specific needs, beliefs and values is foundational to nursing's metaparadigm concepts (Dossey, 2008) and is reflected in many nursing theories highlighting the therapeutic relationship between the nurse and patient: Levine, Orlando, Peplau, Parse, and Travelbee, (as cited in Parker & Smith, 2010). For the purposes of this project, the definition established by the Institute for Patient and Family Centered Care (IPFCC) will be used. They define *patient-and family-centered care* as: "an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually benefiting partnerships between healthcare providers, patients, and families" (IPFCC, 2014). This definition promoting the advancement of patient-and family-centered care to the engagement, partnership and participatory level can be applied to both the individual and institutional level with the aim of achieving quality outcomes in any setting.

Several organizations are notably recognized for their foundational efforts in advancing patient-centered care across healthcare settings. From the United States, the Picker Institute is known for their early work in identifying eight key dimensions of patient-centered care: respect for patients' values, preferences and expressed need, emotional support, physical comfort, information communication and education, continuity and transition, coordination and integration of care, and access to care (Gerteis & Picker, 1993). The Institute for Patient and Family Centered Care (IPFCC) also in the United States, has produced many seminal documents that are widely referenced on patient centered care such as, *Partnering with Patients and Families*

to Design a Patient-and Family-Centered Health Care System (IPFCC, 2008) and Creating Patient and Family Advisory Councils (IPFCC, 2002). Also, the Institute of Medicine (IOM) with its landmark report, *Crossing the Quality Chasm* (2001) identified patient-centered care as one of the six aims for improving the healthcare system. In Canada, the Registered Nurses Association of Ontario (RNAO) developed a Best Practice Guideline (BPG), *Client Centered Care* (2002) to help organizations facilitate practices that promote achievement of client centered outcomes. The theme of the 2002 RNAO BPG focused on “the experience of the patient from their perspective, minimizing vulnerability and maximizing control and respect” (RNAO, 2002 p.10).

Many healthcare organizations working to enhance the focus of patient engagement in their patient-and family-centered care definitions, are including characteristics of patient engagement that are supported through shared involvement and control in care decisions at both the individual and institutional level (Pelletier & Stichler, 2013). The shift toward this philosophical framework of patient-and family-centered care has elicited profound discussion and changes to the healthcare system. Although the focus of “doing with” and “partnering” with patients and families sits contrary to the paternalistic roots of healthcare, this focus on patient and families at the center of care embraces the values of professional nursing in the past and present.

Patient and Family Engagement

Similar to definitions for patient centered care, there have been many thoughtful attempts at defining patient and family engagement. For the purpose of this project, patient and family engagement is defined as “patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system- direct care, organizational design and governance, and policy making- to improve health and health

care”(Carmen et al., 2013, p.223). This definition for patient and family engagement highlights the importance of patients and families moving from a passive to a more active role throughout the multiple levels of care and similar to the definition of PFCC focuses on the aspect of partnerships between patients and families and healthcare providers.

There is an increasing amount of activity promoting patient engagement at all three levels as described in the definition above; direct care, organizational design and governance, and policy making (National Patient Safety Foundation, 2014). In the past, engaging patients in their own care has been the most common focus of patient engagement efforts (National Patient Safety Foundation, 2014). Nursing has been at the forefront of these efforts by empowering patients and their families with information that is timely and accurate, supporting them as active participants in their care and engaging them in decision making about their health (Pelletier & Stichler, 2014). With the premise that engaging patients and families is now essential to enhancing quality outcomes at the organizational and governance level (National Patient Safety Foundation, 2014), nursing along with the entire healthcare team are compelled to create meaningful roles and opportunities for patient and families to help guide healthcare planning, delivery, education and evaluation (IPFCC, 2008). Recognizing that the experiential knowledge of patients and families is essential to drive system change and create improved health systems, organizations are seeking engagement strategies that go beyond the standard methods of surveys and focus groups (IPFCC, 2011).

Patient and Family Advisory Councils

To create effective and sustainable patient and family centered health care settings governments and professional organizations are advocating for collective and collaborative approaches between healthcare providers and users. Different terminologies such as council,

committee, forum, panel and network are used to describe the attempts at partnerships between healthcare providers and users (The Change Foundation, 2014). For the purposes of this project the term patient and family advisory councils as adopted by Cancer Care Ontario, will be used to describe, “the forum for patients and families to participate as partners in designing system improvements” (Cancer Care Ontario, 2012, p.5).

Many benefits of a patient and family advisory council were described in 2002 by the Institute for Patient and Family Centered Care and are still referenced today in the current literature. These benefits include:

- provides an effective mechanism for receiving and responding to consumer input;
- results in more efficient planning to ensure that services really meet consumer needs and priorities;
- leads to increased understanding and cooperation between patients and families and staff;
- promotes respectful, effective partnerships between patients and families and professionals
- offers a forum for developing creative, cost-effective solutions to problems and challenges faced by the program or organization;
- supplies a link between the program, its surrounding community, and community groups;
- provides increased emotional support and access to information for patients and families.

(IPFCC, 2002)

Five years later, Hubbard, Kidd, Donaghy, McDonald and Kerney (2007) identified a gap in the literature regarding the lack of rigorous evidence to support the benefits of patient and family participation in research, and healthcare services. Hubbard et al. (2007) acknowledged that anecdotal evidence reports benefits of patient and family advisory councils but concluded

that a number of key issues still needed to be addressed. In 2008 the IPFCC found that there was a “growing awareness that to achieve the best outcomes patients and families must be more actively engaged in decision making” (Introduction p.v). Although many healthcare organizations are moving toward the patient and family advisory council model, what remains unclear is whether there is evidence to suggest if factors that lead to effective and sustainable patient and family advisory councils result in improved patient and health services outcomes.

Methodological Approach

In the following section, I present the steps taken in conducting this literature review that were guided by the process outlined by Whittemore & Knafl (2005) for integrative reviews. Recent literature describing Patient and Family Advisory Councils as a patient and family engagement strategy was reviewed.

Problem Identification Stage

The first stage of the review process is used to bring clarity and definition to the literature review by identifying the purpose of the search (Whittemore & Knafl, 2005). *Patients and families affected by cancer* were identified as the population of interest and *patient and family advisory council, patient and family engagement, and patient and family centered care* were the variables of interest explored from an integral nursing perspective.

Findings will be applied specifically to the Walker Family Cancer Centre (WFCC) where I am currently employed. The new Walker Family Cancer Centre (WFCC) services the oncology needs of the 431 000 residents living in the Niagara Region in Southern Ontario and recently opened in March 2013. This developing Cancer Centre has been actively involved in the initiation of many new programs and initiatives driven by Cancer Care Ontario. Unfortunately, the WFCC does not currently have a process to engage patients and families in the designing,

delivering, and evaluating of these foundational programs and initiatives. Having heard about PFACs from CCO and other regional cancer centres, the senior leadership team at the WFCC are considering the development of an oncology patient and family advisory council as a patient and family engagement strategy at the new WFCC.

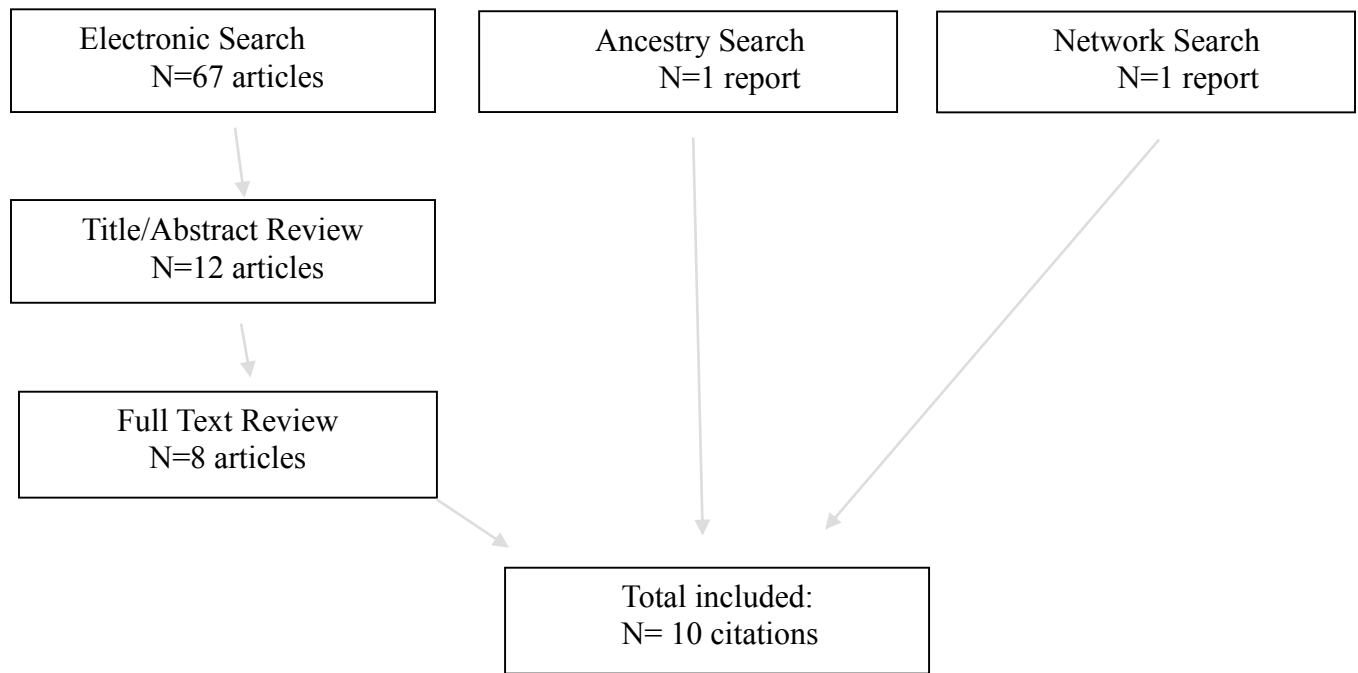
Literature Search Stage

The literature search stage involves the quest for relevant literature on the topic of interest that will be included in the literature review (Whittemore & Knafl, 2005). This literature search was completed using three literature search strategies: searching electronic databases, ancestry searching, and networking. Databases included the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature On-line (Medline) and the Cochrane Database of Systemic Reviews. Combinations of the following terms were used in the literature search: *patient and family advisory council*, *patient advisors*, *PFAC*, and *patient engagement*. Inclusion criteria for the electronic database search included articles published between 2007 and April, 2014, peer reviewed journals, involved human adult participants, and were written in the English language. I choose to include only articles published between 2007 and April 2014 as I was interested to see if there had been any advancement in the level of research conducted since 2007 when Hubbard et al. advocated for more quality evidence to support the advancement of the patient and family involvement agenda.

Refining these search criteria led to a list of 67 potential articles. Titles and abstracts were reviewed for relevance to the topic. Articles were excluded if they referenced only the pediatric patient population, did not reference an acute care hospital or cancer center setting or only referred to engaging the patient in their individualized plan of care and did not address the broader aspect of engaging patients and families in program and organization design,

development, and evaluation of care processes. Fifty- five articles were excluded because they did not meet the search criteria. The full text of the remaining twelve articles was reviewed and eight articles were found to be eligible for inclusion. Once a preliminary list of articles had been established I utilized the ancestry searching approach and “tracked down references cited by relevant sources” (Chumney, n.d.). By searching through the reference list of the predetermined articles, I found an additional piece of literature (The Kings Fund, 2011) completed in the United Kingdom. This report fit the predetermined inclusion and exclusion criteria for this search so I included it as literature to be reviewed. Through networking with one of the Ontario provincial leads on the patient experience, I learned of a research report that was recently published by The Change Foundation (2014) that explored the role PFACs play in facilitating Ontario hospitals to become more patient and family centered. Meeting all the inclusion and exclusion criteria for my search, I included this current report in my selected literature.

Figure 1. Search Results



After reviewing the selected articles found through my search I realized that the bulk of information was not research based and I would not be able to present a diverse perspective including a variety of empirical research and non-research. These search results align with the findings of the Institute for Patient and Family Centered Care (2008) as well as the findings by Hubbard et al. (2007) when they acknowledged that the basis for the patient-centered care movement was not based on empirical evidence but the agenda was supported and promoted because it seemed like the “right thing” to do. However, as patients and families continue to become more involved in the planning, delivery and evaluation of healthcare services there will be an increasing need for measures to evaluate their impact (Mockford, Staniszewaska, Griffiths, & Herron-Marx, 2012).

Data Evaluation Stage

The goals of the data evaluation stage are to evaluate the overall quality of the selected studies (Whittemore & Knafl, 2005). Whittemore and Knafl (2005) address the complexity of evaluating diverse data and suggest that two quality instruments could be used in the case where both sources of literature exist. Since nine of the existing primary sources for this literature review were of a similar non-research design, the Johns Hopkins Nursing Evidence-Based Practice Appendix F: Non-Research Evidence Appraisal tool (Dearholt & Dang, 2012) was selected to provide a standardized method of evaluating the non-research literature. I similarly selected the Johns Hopkins Nursing Evidence-Based Practice Appendix E: Research Evidence Appraisal Tool (Dearholt & Dang, 2012) as a second quality criteria instrument to evaluate the one research report that was included in the review. The Johns Hopkins Nursing Evidence-Based Practice (JHNEBP) appraisal tools attached as Appendix A and B were used to critically examine relevant articles for the strength of evidence and quality rating if appropriate. An evidence level

indicating the strength of evidence based on the design or type of research or non-research from one to five was assigned: evidence Level I was considered high and Level V was considered low. The quality rating if appropriate was reflected by a letter: high (A), good (B) or low/ major flaws (C) (Appendix A and B).

After evaluating the literature I quickly recognized that the strength of the evidence of the selected literature as critiqued by the JHNEBP appraisal instruments was considered low as only one report would be considered a Level III and the rest would be considered the lowest strength of evidence at a Level V. The quality rating of the literature would also be considered low with literature ratings only reflecting “B” (good) and “C” (low/major flaws) (Appendix A and B). Considering the paucity of empirical research available on this topic, the evidence that is required to confidently generalize the finding of PFACs on improved health services outcomes as well as key practices for effective PFACs is currently not available.

Data Analysis Stage

The data analysis stage involves ordering, coding, categorizing and summarizing data from primary sources into a unified conclusion about the research problem (Whittemore & Knafl, 2005). In order to provide a thorough and unbiased interpretation of the selected evidence, the chosen articles were categorized into types of research and non- research evidence. The limited literature on PFACs that was found included three different types of methodologies to be included in the analysis: one mixed method report involving a survey study and a qualitative approach, one organizational experience, and eight expert opinion or case reports. Initially, the selected articles were read through in their entirety to acquire a comprehensive understanding of the content. Next, I reviewed the articles using highlighters and coloured “sticky notes” with the goal of identifying and extracting tentative themes. To help focus the data, categories were

created to provide a manageable framework for the data (Appendix C). Each category was labelled with a term or phrase that described a concept related to the organizations experience with PFACs. I created four categories: key operating practices to make councils more effective, outcomes of PFAC, challenges, and conclusions. An inductive approach was taken when analyzing the selected literature in an attempt to describe and explore the experience of organizations with PFACs. Through the processes of reflexivity and bracketing I was aware of how my personal understanding and perspective of PFACs may influence the analysis of the selected literature. A reflective journal was kept to write down thoughts and concepts as I continued to analyze the literature. The journal filled with mind maps, charts and word pictures evolved through my early attempts at analyzing the literature and was very helpful in keeping me focused and allowed me to thoughtfully develop the identified themes and patterns amid the array of experiences of different organizations with PFACs.

Literature Findings

Understanding that the selected literature was not empirically based it was still interesting to find that the literature did reveal some common perspectives. Three broad themes emerged upon review of the selected literature: key practices required to develop and sustain an effective PFAC, challenges experienced by organization with PFAC's, and identified outcomes since implementation of PFAC. These broad themes will be described including the more specific subthemes that developed.

Table 1

PFAC Findings from the Literature

Themes	Subthemes
Key Practices of Effective PFACs	<ul style="list-style-type: none"> ● Advancing the culture of PCCC ● Strategic recruitment of PFAC members ● Skilled Chair/Co-chair and meetings ● Feedback loop and senior leadership support
Challenges of PFACs	<ul style="list-style-type: none"> ● Working relationships between patients and staff ● PFAC visibility within the organization ● Ongoing recruitment and engagement of PFAC members ● Measuring and evaluation
Outcomes of PFACs	<ul style="list-style-type: none"> ● Patient <ul style="list-style-type: none"> ▪ Improved patient experience ▪ Improved treatment of the whole person ▪ Patients felt their voice was heard ▪ Patients found meaning in being able to work toward changes that would improve the experience for future patients ▪ Increase in patient satisfaction ● Staff <ul style="list-style-type: none"> ▪ Staff grew to appreciate the benefits of collaborating with patients and families ▪ A sense of trust developed between staff and PFACs ▪ Staff raised new ideas for PFAC involvement ▪ Increased sensitivity toward the patient experience ● Organization <ul style="list-style-type: none"> ▪ Decreased law suits ▪ Decreased length of stay ▪ PFACs became more involved with complex issues ▪ Extensive and sustained changes

Key Practices Required to Develop an Effective PFAC

All organizations identified fundamental practices they discovered to be crucial to the effectiveness and success of their PFACs. Historically, PFAC implementations have not always been effective or sustainable (The Change Foundation, 2014; The King’s Fund, 2011; White, 2012); thus the literature emphasizes the importance of establishing a plan that positions the

council for success rather than creating an advisory board that is merely a “window dressing” or formality (White, 2012). Establishing a PFAC as a patient engagement strategy with the aim of improving and redesigning health services to improve the patient experience requires a comprehensive and collaborative approach (Haycock & Wahl, 2013; Meyers, 2008; Warren, 2012; White, 2012; Zarubi, Reiley, & McCarter, 2008).

Advancing the culture of PCCC within the organization.

Many authors spoke of the importance of establishing or advancing the organizational culture of PCCC (Meyers, 2008; Taloney & Flores, 2013; The Change Foundation, 2014; Zarubi et al., 2008). In order for a PFAC to be successful within the organization, the staff and healthcare leaders must believe that patients and families are an integral part of the healthcare team that have experiential knowledge and valuable information to contribute (Meyers, 2008; Taloney & Flores, 2013; Warren, 2012). Leaders and staff must be prepared to work together with patients and families as partners or equals on organizational service improvement and quality and safety initiatives (Haycock & Wahl, 2013; The King’s Fund, 2011; Zarubi et al., 2008).

Strategic recruitment of PFAC members.

Recruitment of committed and effective PFAC participants is crucial to the success and sustainability of a PFAC (Change Foundation, 2014; The King’s Fund, 2011; Meyers, 2008; White, 2012; Willis, Kritchlen, Eldredge, & Carney, 2013). Both staff and patient and family advisors must be engaged with the improvement projects and processes (The King’s Fund, 2011). Advisors must be able to see beyond a problem and not take things personally, be willing to listen to all feedback, embrace diversity and work toward a solution (Meyers, 2008; The Change Foundation, 2014; Willis et al., 2013; Zurubi et al., 2008). PFAC participants must bring good communication skills, good judgment, and the ability to represent others, and offer a

generic patient voice (Meyers, 2008; Warren, 2012, Willis et al., 2013; Zarubi et al., 2008). A blend of senior leaders, clinical leaders and frontline staff as well as patients and families is deemed essential to move initiatives forward and ensure ongoing communication to drive and sustain change throughout the organization (The Change Foundation, 2014; Haycock & Wahl, 2013; The King's Fund, 2011; Meyers, 2008; Warren, 2012). The involvement of senior leadership on the council is considered crucial to ensure ongoing support and resources for the PFAC (The Change Foundation, 2014; Zarubi et al., 2012).

The ratio of patient and family participants to staff participants varied among organizations but all groups support at least a 1:1 ratio with 2:1 as the average in favour of more patient and family members than staff. The number of participants on the council also varied but averaged between groups of ten to twenty. A multipronged or wide system approach to recruitment is proposed as most successful in creating a diversified group with broad representation of the service users (The King's Fund, 2011). PFAC participants are often asked to make a two year commitment to the council with an option to renew their term (Taloney & Flores, 2013; Warren, 2012; Zarubi et al., 2008). The element of trust and productive working relationships among the members is recognized as key to a council's success as members spend time listening to each other and providing thoughtful feedback (The Change Foundation, 2014; Warren, 2012; Zarubi et al., 2008). Another practice designed to keep the PFAC fresh and relevant is the regular integration of new members allowing for addition of new members throughout the year which compensates for attrition and disengagement of some members (White, 2012).

Skilled chair/co-chair and meetings.

There are many different configurations of PFAC chair and co-chair described in the literature. These positions are filled by both staff and patient and family members but

interestingly The Change Foundation (2014) found that seasoned and experienced PFAC's had exclusively patient and family members as chairs. The desirable skills and attributes of these leaders are identified as: the ability to lead and run an effective meeting (The Change Foundation, 2014; Warren, 2012); experience and skill in group communications; conveying understanding and empathy (The Change Foundation, 2014; Warren, 2012); skills in prioritizing and multi-tasking (The Change Foundation, 2014); and insight and ability to problem solve complex issues (The Change Foundation, 2014).

Formal meetings have been found to be most effective where agendas are circulated ahead of time and minutes are kept for future reference and tracking (Warren, 2012). Whether led by a staff person or patient or family member, the meeting must be well planned and facilitated in order for participants to feel that their time is valued and respected (The Change Foundation 2014; Warren, 2012; White, 2012). Clear goals and purpose of the council as well as one or two well defined projects should be selected to focus on at a time (The King's Fund 2011; Warren, 2012; Willis et al., 2013). Food is often provided prior to or during the meeting to facilitate conversation and comfort among members (Taloney & Flores, 2013; Warren, 2012; Zarubi et al, 2008).

Feedback loop and senior leadership support.

Effective and sustainable PFAC's require dedicated time, resources, engagement and enthusiasm (The King's Fund, 2011). Taking the time to engage and obtain the support of leaders at the administrative level helps to ensure that the human and financial resources required to implement proposed changes throughout the organization will be available (The Change Foundation, 2014; Zarubi et al., 2012). Leadership engagement also sets the expectation that these councils are not just formalities but are positioned as groups with power to make important

changes (The Change Foundation, 2014; Haycock, 2012, Zarubi et al., 2008). CEOs, heads of nursing or other clinical departments as well as other senior leadership staff in the organization are not only engaged for their support but are often sought after as PFAC members or even co-chairs, to ensure that the council has the authority to move initiatives forward (The Change Foundation, 2014). Engaging leaders and staff at all levels throughout the organization creates a strong infrastructure for the council and facilitates a continuous feedback loop between patient and family advisor and hospital leaders (The Change Foundation, 2014; White, 2012; Zarubi et al., 2008). When it is not possible to involve senior leadership directly on the council it is necessary to establish reporting practices that are reflected in the institutions hierarchical structure and designate the communication role to a PFAC member (The Change Foundation, 2014). The sharing of PFAC activities and initiatives both internally and externally to the organization is deemed essential to sustain progress and momentum of the PFAC (The Change Foundation, 2014; Haycock, 2013; Meyers, 2008). This reciprocal and active communication loop is important to ensure council members feel their time and efforts are valued, they are being listened to and are contributing to positive change that can be implemented within the organization (Haycock & Wahl, 2013; Warren 2012).

Challenges Experienced by Organizations with PFACs

Examining the theme of challenges experienced by organizations with PFACs throughout the data analysis phase both excited and motivated me as I soon recognized that the key practices required to achieve an effective PFAC described above could be considered part of the solution to the identified challenges below. The willingness of trailblazing organizations to share openly about some of the difficulties encountered with PFACs has allowed those that follow the opportunity to establish practices to prepare and prevent potential barriers to success. Barriers

have been raised from all perspectives: patient, staff and organizations that potentially could be detrimental to the effectiveness of a PFAC if not addressed.

Several authors reported that staff were hesitant and reluctant to engage with patients and families as equal partners; they questioned the appropriateness of empowering patients and families in organizational decision making (Haycock & Wahl, 2013; White, 2012; Warren, 2012; Willis et al. 2013; Zarubi et al., 2008). Some healthcare providers described working with patients and families as uncomfortable and thus were averse to speaking openly about issues, identifying the fear of litigation as a factor (Warren, 2012). As well, feelings of being vulnerable to the opinions of patients and families were noted (Willis et al, 2013). Staff were also reported as not engaged or committed if suggested improvements were not part of their main roles or responsibilities (The Change Foundation, 2014; The Kings Fund, 2011). Overall, organizational cultural resistance has been reported as a major barrier to the ongoing collaboration and engagement with patients and families in the improvement of healthcare systems.

Patients and families participating on the council reported feeling that the council did not have the visibility that it required within the organization to move the initiatives forward and thus volunteer members became discouraged and stopped participating (The Change Foundation, 2014). On the other hand when councils were integrated well into the organization some council members reported being over burdened with work and were subject to participant burnout (The Change Foundation, 2014).

From the organization perspective, when trying to move ahead with patient and family advisory councils the ongoing recruitment and engagement of appropriate patients and family members has been described as challenging (The Change Foundation, 2014; Warren 2012; Willis et al., 2013). The aim- to utilize patient and family perspectives to shape effective future

solutions requires patient and family members who are willing to move past their own healthcare experience and provide constructive input (White, 2012). Even though potential advisors are screened, their motives were not always apparent during the screening process. PFAC members who come with their own agenda or “axe to grind” are often incapable of seeing the bigger picture and have difficulty collaborating with the intent of improving the patient experience for future patients and families (Warren, 2012; White, 2012).

Measuring and evaluating PFAC activities and outcomes are recognized as a high priority, yet it has been described as difficult to measure the impact of councils directly as they work in partnership and are considered a part of organizational wide efforts (The Change Foundation, 2014; White, 2012). The Change Foundation (2014) found that tools to monitor input and ideas are common, but evaluation processes to monitor impact are scarce. It is evident that it takes time to gauge the system wide impact of PFACs as many councils continue to struggle to provide the evidence needed to show the impact of their work (The Change Foundation, 2014; Haycock, 2012). However, I believe that as health care organizations move past the historical confines of unilateral practice and begin to include patients and families as allies in quality and improvement initiatives, the improvement of care and services will follow.

Outcomes of PFACs

Understanding the challenges of providing empirical evidence that identifies correlation between PFACs and positive organizational outcomes, the selected articles reviewed have clearly acknowledged the positive impact of PFACs in their organizations. It is apparent that PFACs positioned as partners and the voice of patients throughout the healthcare continuum, are starting to contribute to the healthcare system at all system levels: patient, staff and organization.

At the patient level, an increase in patient satisfaction results often followed the implementation of a PFAC (Haycock, 2012; Meyers, 2008; Warren, 2012). The Change Foundation (2014) described how newer PFACS often focused on small issues such as parking, visiting hours, signage and way finding that resulted in an improved patient experience. Similarly, Meyer (2012), White (2012), and Zarubi, Reiley and McCarter (2008) also spoke of the small inexpensive initiatives that PFACs were involved in such as menu planning and timing of meals that made a big difference to the patient experience. Warren (2012) noted how when family advisors had the opportunity to share their story there was an increased attention placed on relieving fear and anxiety that resulted in improved treatment of the whole person. Many of the selected articles also spoke of how the implementation of a PFAC created an enabling environment where patients felt their voice was heard, a place where the advice of patient's informs decisions (The Change Foundation, 2014; Taloney & Flores, 2013; Warren, 2012; Willis et al, 2013). Patient and families who had opportunity to participate with PFACs found meaning in being able to work toward changes that would improve the experience for patient patients and families to come (The Change Foundation, 2014). Positive staff outcomes were apparent as the staff became more comfortable partnering and collaborating with Patient and Family Advisory Councils. As nurses and healthcare team members began to witness how PFACs improved patient outcomes the staff grew to appreciate the benefits of collaborating with patient and families (The King's Fund, 2011; Meyers, 2008; Zarubi et al., 2008). A sense of trust was reported to develop among the staff as they had opportunity to work with PFACs (The King's Fund, 2011; Meyers, 2008; Taloney & Flores, 2013; Zarubi et al, 2008). Moreover, as staff members started working with patient advisors they raised new ideas, roles and opportunities for PFAC involvement both from within their program and throughout the organization (The Change

Foundation, 2014; Zarubi et al., 2008). New skills in listening, learning, and partnering are cultivated as healthcare providers strive to understand the patient perspective. Patients and families have been instrumental in helping healthcare professionals view healthcare encounters from a patient vantage point resulting in an increased sensitivity toward the patient experience (Taloney & Flores, 2013; Warren, 2012).

In conjunction with the advancement of the patient-centered care agenda and the implementation of PFACs, hospitals have reported many positive organization outcomes. Decreased law suits (Meyers, 2008), decreased length of stay (Warren, 2012), and an overall improvement of the patient experience has been described (Meyer, 2008; Taloney & Flores, 2013; Zarubi et al., 2008). As organizations become more experienced working with PFACs, PFACs were noted to be involved with more complex issues including reviewing corporate and policy issues, revamping educational programs and patient information strategies, and participating in staff interview panels and clinical and hospital redesign initiatives (The Change Foundation, 2014). Also, there was an increase in PFAC's noted throughout the organization as individual programs started working collaboratively with PFACs and sharing their success stories (Zarubi et al., 2008). Ultimately, healthcare organizations who are intentionally collaborating with patients and families as partners and advisors to design, deliver, and evaluate their healthcare services are reporting extensive and sustained changes (Haycock & Wahl, 2013; The Kings Fund 2011).

Discussion

This literature review provides an analysis and review of the early reports from organizations that are engaging patients and families in PFACs. It has been interesting to note that after reviewing the literature from three different countries there are common foundational elements

proposed for organizations to consider when planning for an effective and sustainable PFAC, as well as common challenges that must be overcome. While the literature is beginning to show that the involvement of patients and families in efforts to improve healthcare services is resulting in new and improved services (Mockford et al, 2011), the question to determine if the engagement of patients and families through a PFAC leads to improved patient, staff, and organizational outcomes was unable to be answered due to the lack of research evidence available on this narrow topic. If I were to continue my search at this time I would broaden my search terms to capture the work that is being done on patient and public engagement. I think including search terms like *partnering*, *collaboration*, *involvement*, *service user*, and different combinations of *engagement* may help capture more of the research that is being done on engaging patients and families in the improvement of health services. I would also include more databases and extend the years of my search. Understanding that the research on this form of patient engagement is relatively scarce yet forthcoming, I would spend more time completing an environment scan to become more familiar with the grey literature that is available.

As PFACs are being positioned as a patient engagement strategy that supports healthcare organizations in reaching the highest level of patient engagement- partnership (Born & Laupacis, 2012), there is considerable opportunity to improve on the measurement and evaluation of this patient engagement strategy.

Implication of Findings for Nursing

Learning from individual experiences and patient perceptions is one of the essential elements in providing patient- centered care and a key underpinning in planning for an effective patient and family advisory council. Nursing has embraced the multiple ways of knowing philosophy that has come with post modernism by acknowledging that knowing arises from personal

experience and knowledge (Dossey, 2008). Thus, the patient having experienced the healthcare journey becomes the “expert” of his or her experiences, and is a key resource for nursing and the healthcare team in planning for future quality initiatives. Positioning the patient and family as equal partners in the development and redesigning of healthcare programs allows for a collaborative and participatory vision that nurses value and strive for. Understanding the value of the patient-centered approach to care, all nurses need to step up and lead the interprofessional team toward embracing a culture of patient-centered care and patient engagement. Nurses, having developed a therapeutic relationships with their patient know their patients well thus are well positioned to be involved in the strategic recruitment of PFAC members by suggesting suitable PFAC candidates. Nurses will not only benefit from the work that will come from the implementation of patient engagement strategies like a PFAC, advanced practice nurses are well positioned to lead in the development, implementation and ongoing success of a Patient and Family Advisory Council.

Role of the APN in Planning and Sustaining a PFAC

By operating in all of the three spheres of influence the APN can facilitate the effectiveness and successful integration of PFACs in an organization by: empowering patient and families as equal partners, educating staff and physicians to work collaboratively with patients and families, and supporting organizational and policy-level changes (Fulton, Lyon & Goudreau, 2010).

Patient/Client Sphere of Influence

Through a holistic and integrated approach, the advanced practice nurse (APN) works in partnership with the patient and family to empower them as equal partners in healthcare planning and redesign (CNA, 2008). APN’s recognize the family as a dynamic system that experiences the healthcare system alongside the patient and understands that the experience of care from the

patient and family viewpoint is vitally important. Valuing the patient and family perspective, the APN working with an integral nursing lens will consider the experience goals of patients and families on an equivocal level as process and clinical goals. Knowing that a patient experience is an individual subjective phenomenon that cannot be directly observed or accessed, the APN recognizes that only the words and language of the patient or family, when reflecting back on an event, can describe or reconstruct the happenings that they journeyed through (Bate & Robert, 2006). By facilitating opportunities and encouraging patients and families to share their story with the healthcare team for the purpose of learning and gaining new knowledge, the APN positions patients and families as integral partners in healthcare improvement and redesign and can support strategic recruitment of PFAC members.

Nurses and Nursing Practice Sphere of Influence

The APN is well positioned to develop, support and implement a vision for nursing practice that values the patient voice and facilitates partnerships between nurses and the patients they serve (CNA, 2008). From an integral nursing perspective the APN works from the “We” or “intersubjective” space where the APN as a leader, encourages other nurses and team members to partner with patients and families in the planning and designing of the organizations healthcare services advancing the culture of PFCC. Through well planned PFAC meetings the APN utilizing a collective leadership approach allows the healthcare team members along with patients and families to put forth their perspectives and experiences on an equal footing. This partnership enhances collaborative practice where patients, families and healthcare team members, contributing varied perspectives, work toward a shared vision for quality care and services. Appreciating and valuing multiple perspectives, the APN has the knowledge and skill to reframe often contradictory perspectives (CNA, 2008) thus allowing members of the PFAC to feel that

their input is valued and heard as they provide insights into how health services can be provided at both the departmental and organizational levels. The APN has a pivotal role in partnering with patients, families and health care team members to educate and facilitate change and practice within the healthcare setting that leads to optimal patient outcomes and an enhanced patient experience (CNA, 2014).

Organization/System Sphere of Influence

Engaging patient and families in healthcare planning and design involves organizational and system level change. Advocating for change in health policy and design to improve the patient experience, the APN, working from an integral nursing perspective, works from the interobjective or “Its” space. By consulting and collaborating with members of the leadership team the APN strives to advance the culture of patient-centered care within the organization. Throughout these collaborative efforts the APN can be positioned as an integral link creating a feedback loop between the PFAC and organizational leadership team and can be involved in facilitating and managing the proposed changes and initiatives throughout the organization that have been designed by the PFAC. By understanding and integrating the principles of resource allocation and cost effectiveness, the APN is positioned to partner with the organization to ensure there are ongoing funds and resources dedicated to patient and family engagement opportunities.

In summary, the advanced practice nursing role in planning and sustaining an effective Patient and Family Advisory Council necessitates the influence of the three spheres or levels of Clinical Nurse Specialist (CNS) practice. Through analyzing, synthesizing and applying nursing knowledge, theory and research evidence the APN can nurture system wide changes specifically, the integration of successful PFACs which model integral partnerships between patients and families, nursing and healthcare teams, and organizations. These integral partnerships have the

potential to develop, design and evaluate the quality health care services that patients throughout Canada so deserve.

Areas for Future Research

PFACs are one engagement strategy that many Canadian hospitals are exploring or considering integrating. This literature review has demonstrated that presently there is a paucity of empirical research to support the implementation of this type of patient and family engagement strategy. As PFACs are established there needs to be ongoing commitment to the evaluation and monitoring of this approach as well as development of instruments to measure the impact of patient engagement (Mockford et al., 2012). Are PFACs the sole answer to reach the partnership level of patient and family engagement (Born & Laupacis, 2012) or are there other complementary mechanisms that will enhance the engagement of patients and families who are unable or unwilling to serve on this type of council? If PFACs are a reliable method of engaging patients in designing, developing and evaluating health care services, what is the best strategy to integrate them? Can other improvement based initiatives such as experienced based co- design complement or enhance the outcomes of a PFAC?

There are many questions that still need to be studied regarding the engagement of patients and families in the designing, delivery, and evaluation of healthcare services. Nevertheless, when patient and family centered care and engagement are promoted and valued, and patients and families are involved at all levels of the organization, the health service outcomes can only get better.

Dissemination of Findings

The findings of this literature review and project will be presented during my oral exam for the degree of Master's in Nursing. I will also present the findings of this review to the senior

team at the Walker Family Cancer Centre as they anticipate the development of a Patient and Family Advisory Council to assist in providing quality oncology services for the residents of Niagara. I also hope to be able to present the findings of this review to the staff of the Walker Family Cancer Centre during a lunch and learn in preparation for the collaborative effort that will be required to plan, develop, and sustain a PFAC at the WFCC. If the opportunity presents itself I would consider reframing this project as a poster presentation for a conference.

Conclusions

Through the study of the advancement of the patient-centered care agenda and the engagement of patients and families in the design, delivering, and evaluation of health services I have learned that patients and families are indeed essential allies in the improvement of quality healthcare services.

Hospitals that listen to and partner with their patients and families can gain tremendous insights from the user experience. This new knowledge can in turn be used to redesign the services that are provided or create new services which can result in an improved patient experience, increased patient satisfaction, increased sensitivity of staff toward the patient experience and extensive and sustained changes throughout the organization. By engaging patients and families through the model of PFACs, organizational experience is starting to show that things should be done differently, that things can be done better (Haycock, 2012).

Although PFACs are continuing to be promoted as a patient engagement strategy and are leading practice changes that improve the experience of patients as they move through the health care system, there is still much to be learned about the impact that PFACs have on an organization as well as patient and staff outcomes; clearly more research is needed. Ultimately, these literature review findings could be used as a foundation for a future research project

initiative to advance the knowledge and evidence of PFACs as a patient and family engagement strategy.

Nonetheless, through the advancement of PFCC and patient engagement strategies such as Patient and Family Advisory Councils, patients and families have shown healthcare organizations that the journey toward improved health systems and services is most successful when taken together (Warren, 2012).

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Appendix A

Johns Hopkins Nursing Evidence-Based Practice
Appendix E: Research Evidence Appraisal Tool

Evidence Level and Quality: _____

Article Title:		Number:	
Author(s):		Publication Date:	
Journal:			
Setting:		Sample (Composition & size):	
Does this evidence address my EBP question?	<input type="checkbox"/> Yes	<input type="checkbox"/> No Do not proceed with appraisal of this evidence	
Level of Evidence (Study Design)			
A. Is this a report of a single research study? <i>If No, go to B.</i>			
1. Was there manipulation of an independent variable?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
2. Was there a control group?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
3. Were study participants randomly assigned to the intervention and control groups?		<input type="checkbox"/> Yes	<input type="checkbox"/> No
If Yes to all three, this is a Randomized Controlled Trial (RCT) or Experimental Study		→ <input type="checkbox"/> LEVEL I	
If Yes to #1 and #2 and No to #3, OR Yes to #1 and No to #2 and #3, this is Quasi Experimental (some degree of investigator control, some manipulation of an independent variable, lacks random assignment to groups, may have a control group)		→ <input type="checkbox"/> LEVEL II	
If No to #1, #2, and #3, this is Non-Experimental (no manipulation of independent variable, can be descriptive, comparative, or correlational, often uses secondary data) or Qualitative (exploratory in nature such as interviews or focus groups, a starting point for studies for which little research currently exists, has small sample sizes, may use results to design empirical studies)		→ <input type="checkbox"/> LEVEL III	
NEXT, COMPLETE THE BOTTOM SECTION ON THE FOLLOWING PAGE, "STUDY FINDINGS THAT HELP YOU ANSWER THE EBP QUESTION"			

**Johns Hopkins Nursing Evidence-Based Practice
Appendix E: Research Evidence Appraisal Tool**

<p>B. Is this a summary of multiple research studies? <i>If No, go to Non-Research Evidence Appraisal Form.</i></p> <p>1. Does it employ a comprehensive search strategy and rigorous appraisal method (Systematic Review)? <i>If No, use Non-Research Evidence Appraisal Tool; if Yes:</i></p> <p style="margin-left: 20px;">a. Does it combine and analyze results from the studies to generate a new statistic (effect size)? (Systematic review with meta-analysis)</p> <p style="margin-left: 20px;">b. Does it analyze and synthesize concepts from qualitative studies? (Systematic review with meta-synthesis)</p> <p style="margin-left: 40px;"><i>If Yes to either a or b, go to #2B below.</i></p> <p>2. For Systematic Reviews and Systematic Reviews with meta-analysis or meta-synthesis:</p> <p style="margin-left: 20px;">a. Are all studies included RCTs? → <input type="checkbox"/> LEVEL I</p> <p style="margin-left: 20px;">b. Are the studies a combination of RCTs and quasi-experimental or quasi-experimental only? → <input type="checkbox"/> LEVEL II</p> <p style="margin-left: 20px;">c. Are the studies a combination of RCTs, quasi-experimental and non-experimental or non-experimental only? → <input type="checkbox"/> LEVEL III</p> <p style="margin-left: 20px;">d. Are any or all of the included studies qualitative? → <input type="checkbox"/> LEVEL III</p>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<p>COMPLETE THE NEXT SECTION, "STUDY FINDINGS THAT HELP YOU ANSWER THE EBP QUESTION"</p> <p>STUDY FINDINGS THAT HELP YOU ANSWER THE EBP QUESTION:</p> <div style="border: 1px solid black; height: 150px; margin-top: 5px;"></div>				

NOW COMPLETE THE FOLLOWING PAGE, "QUALITY APPRAISAL OF RESEARCH STUDIES", AND ASSIGN A QUALITY SCORE TO YOUR ARTICLE

Appendix B

**Johns Hopkins Nursing Evidence-Based Practice
Appendix F: Non-Research Evidence Appraisal Tool**

Evidence Level & Quality: _____

Article Title:		Number:	
Author(s):		Publication Date:	
Journal:			
Does this evidence address the EBP question?		<input type="checkbox"/> Yes	<input type="checkbox"/> No Do not proceed with appraisal of this evidence
<input type="checkbox"/> Clinical Practice Guidelines: Systematically developed recommendations from nationally recognized experts based on research evidence or expert consensus panel. LEVEL IV			
<input type="checkbox"/> Consensus or Position Statement: Systematically developed recommendations based on research and nationally recognized expert opinion that guides members of a professional organization in decision-making for an issue of concern. LEVEL IV			
<ul style="list-style-type: none"> • Are the types of evidence included identified? • Were appropriate stakeholders involved in the development of recommendations? • Are groups to which recommendations apply and do not apply clearly stated? • Have potential biases been eliminated? • Were recommendations valid (reproducible search, expert consensus, independent review, current, and level of supporting evidence identified for each recommendation)? • Were the recommendations supported by evidence? • Are recommendations clear? 		<input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No
<input type="checkbox"/> Literature Review: Summary of published literature without systematic appraisal of evidence quality or strength. LEVEL V			
<ul style="list-style-type: none"> • Is subject matter to be reviewed clearly stated? • Is relevant, up-to-date literature included in the review (most sources within last 5 years or classic)? • Is there a meaningful analysis of the conclusions in the literature? • Are gaps in the literature identified? • Are recommendations made for future practice or study? 		<input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No
<input type="checkbox"/> Expert Opinion: Opinion of one or more individuals based on clinical expertise. LEVEL V			
<ul style="list-style-type: none"> • Has the individual published or presented on the topic? • Is author's opinion based on scientific evidence? • Is the author's opinion clearly stated? • Are potential biases acknowledged? 		<input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No

**Johns Hopkins Nursing Evidence-Based Practice
Appendix F: Non-Research Evidence Appraisal Tool**

Organizational Experience:			
<input type="checkbox"/> Quality Improvement: Cyclical method to examine organization-specific processes at the local level. LEVEL V			
<input type="checkbox"/> Financial Evaluation: Economic evaluation that applies analytic techniques to identify, measure, and compare the cost and outcomes of two or more alternative programs or interventions. LEVEL V			
<input type="checkbox"/> Program Evaluation: Systematic assessment of the processes and/or outcomes of a program and can involve both quantitative and qualitative methods. LEVEL V			
Setting:		Sample (composition/size):	
<ul style="list-style-type: none"> • Was the aim of the project clearly stated? • Was the method adequately described? • Were process or outcome measures identified? • Were results adequately described? • Was interpretation clear and appropriate? • Are components of cost/benefit analysis described? 		<input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> N/A
<input type="checkbox"/> Case Report: In-depth look at a person, group, or other social unit. LEVEL V			
<ul style="list-style-type: none"> • Is the purpose of the case report clearly stated? • Is the case report clearly presented? • Are the findings of the case report supported by relevant theory or research? • Are the recommendations clearly stated and linked to the findings? 		<input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> No
Community Standard, Clinician Experience, or Consumer Preference			
<input type="checkbox"/> Community Standard: Current practice for comparable settings in the community LEVEL V			
<input type="checkbox"/> Clinician Experience: Knowledge gained through practice experience LEVEL V			
<input type="checkbox"/> Consumer Preference: Knowledge gained through life experience LEVEL V			
Information Source(s):		Number of Sources:	
<ul style="list-style-type: none"> • Source of information has credible experience. • Opinions are clearly stated. • Identified practices are consistent. 		<input type="checkbox"/> Yes <input type="checkbox"/> Yes <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/> No <input type="checkbox"/> N/A
Findings that help you answer the EBP question:			

**Johns Hopkins Nursing Evidence-Based Practice
Appendix F: Non-Research Evidence Appraisal Tool**

<p>QUALITY RATING FOR CLINICAL PRACTICE GUIDELINES, CONSENSUS OR POSITION STATEMENTS (LEVEL IV)</p> <p>A High quality: Material officially sponsored by a professional, public, private organization, or government agency; documentation of a systematic literature search strategy; consistent results with sufficient numbers of well-designed studies; criteria-based evaluation of overall scientific strength and quality of included studies and definitive conclusions; national expertise is clearly evident; developed or revised within the last 5 years.</p> <p>B Good quality: Material officially sponsored by a professional, public, private organization, or government agency; reasonably thorough and appropriate systematic literature search strategy; reasonably consistent results, sufficient numbers of well-designed studies; evaluation of strengths and limitations of included studies with fairly definitive conclusions; national expertise is clearly evident; developed or revised within the last 5 years.</p> <p>C Low quality or major flaws: Material not sponsored by an official organization or agency; undefined, poorly defined, or limited literature search strategy; no evaluation of strengths and limitations of included studies, insufficient evidence with inconsistent results, conclusions cannot be drawn; not revised within the last 5 years.</p>
<p>QUALITY RATING FOR ORGANIZATIONAL EXPERIENCE (LEVEL V)</p> <p>A High quality: Clear aims and objectives; consistent results across multiple settings; formal quality improvement or financial evaluation methods used; definitive conclusions; consistent recommendations with thorough reference to scientific evidence</p> <p>B Good quality: Clear aims and objectives; formal quality improvement or financial evaluation methods used; consistent results in a single setting; reasonably consistent recommendations with some reference to scientific evidence</p> <p>C Low quality or major flaws: Unclear or missing aims and objectives; inconsistent results; poorly defined quality improvement/financial analysis method; recommendations cannot be made</p>
<p>QUALITY RATING FOR LITERATURE REVIEW, EXPERT OPINION, COMMUNITY STANDARD, CLINICIAN EXPERIENCE, CONSUMER PREFERENCE (LEVEL V)</p> <p>A High quality: Expertise is clearly evident; draws definitive conclusions; provides scientific rationale; thought leader in the field</p> <p>B Good quality: Expertise appears to be credible; draws fairly definitive conclusions; provides logical argument for opinions</p> <p>C Low quality or major flaws: Expertise is not discernable or is dubious; conclusions cannot be drawn</p>

Appendix C

Summary of Literature Findings

Author and Publication	Type of Publication	Evidence Level and Quality Rating if appropriate	Pertinent Conclusions and Recommendations
<p>The Change Foundation, (2014). <i>Patient/Family Advisory Councils in Ontario Hospitals: At Work, In Play</i>. Toronto, Canada: The Change Foundation.</p>	<p>Multi method design including both a survey study and a qualitative study with a phenomenological approach.</p> <p>Research Question: What is the state of play with patient and family advisory councils in Ontario hospitals?</p> <p>Survey (n=89) Telephone interviews (n=64)</p>	<p>Level III C</p>	<p><i>Key operating practices to make councils more effective:</i> administrative support, executive-level leadership, strategic recruitment and screening and connection to clinical staff. Skilled chair/co-chair: ability to lead and manage a meeting, skills in prioritizing and multi-tasking, sensitivity to patients’ feelings and insights about the complex issues at hand. Clear feedback loop between PFAC and management</p> <p><i>Outcomes of PFAC:</i> 94% of patient/family members believed the council was an effective way to engage patients and their families. 100% of patient and family participants had a meaningful experience participating on the PFAC. 97% of staff participants found the PFAC experience meaningful.</p> <p><i>Challenges:</i> representativeness, internal visibility, adequate resources, member burnout, recruitment of appropriate members, mechanisms to determine impact of PFAC.</p> <p><i>Conclusions:</i> There is still much to learn around the impact that councils have. More research is needed.</p>

			PFACS throughout Ontario are evolving, developing their roles, and leading practices to improve the experience of patients and caregivers, as they move throughout the healthcare system. The work of PFACs takes considerable time, human and financial resources, and the cooperation of a vast number of stakeholders both internally and externally from the organizations
Haycock, C, (2012). Patient-family councils make the difference. <i>Health Progress</i> , 93(2), 24	Expert Opinion Case Report Describes the experience of a health system in rolling out PFACs across 76 acute care hospitals in the USA	Level V B	<i>Key operating practices to make councils more effective:</i> Purpose was of the council was clear; to make things better. Followed an evidenced based toolkit to guide PFAC implementation and analysis. <i>Outcomes of PFAC:</i> Improved patient satisfaction scores were recorded. Creation of PFACs has helped to model the definition and spread the philosophy of PFCC. <i>Challenges:</i> Takes time to gauge system wide impact of PFAC <i>Conclusions:</i> PFAC's are beginning to show that things should be done differently- highlighting things that should be done better.
Haycock, C., & Wahl, C., (2013) Achieving patient and family engagement through the implementation and evolution of advisory councils across a large health care system. <i>Nursing Administration Quarterly</i> 37(3) 242-246.	Expert Opinion Case Report. Outlines tactical steps to implement a PFAC based on multiple care settings across 19 states in the USA	Level V C	<i>Key Operating Practices to make councils more effective:</i> Partnering with patients and families to develop plans for services. Feedback loops between council and the organization were essential to sustaining progress. The sharing of PFAC innovations and outcomes has sustained the momentum of the PFAC. To measure success, customer satisfaction results

			<p>were shared throughout the year at PFAC meetings. CNO’s role is critical to driving and sustaining change throughout the organization <i>Outcomes:</i> Hospitals with PFACs continue to report extensive and sustained change. <i>Challenges:</i> Development of agenda topics and PFAC activities to engage the groups were initially requested <i>Conclusions:</i> Patients and families are essential partners to improve quality and safety in an organization. Patient engagement efforts need to be incorporated throughout the care continuum to improve quality outcomes and patient centered care.</p>
<p>Kings Fund. (2011). <i>The patient-centred care project</i>. London, England: The Kings Fund</p>	<p>Organizational Experience</p> <p>An Independent Evaluation Report.</p> <p>Completed by an external researcher.</p> <p>Describes the findings from an experience based co-design (EBCD) Project in a Cancer Centre in London, England. (n=1)</p> <p>Both staff and patients were interviewed by a researcher.</p>	<p>Level V B</p>	<p><i>Key operating practices to make councils more effective:</i> Staff and patients working together as equals. A patient experience DVD. An enabling environment where projects were linked with key professionals’ roles and responsibilities. Dedicated resources space and time. Staff engagement and enthusiasm. <i>Outcomes:</i> Very positive feedback on impact of improved patient experience. Significant changes were made in a number of areas. Patients could see changes being made almost immediately. Made specific changes but supported wider system improvements as well. Facilitated better communication across all departments. Participants felt they had both personal benefit and organizational benefit.</p>

	<p>Patient interviews were filmed and viewed by staff and patients for improvement opportunities</p>		<p><i>Challenges:</i> Organizational politics. Key staff not engaged, personnel changes, lack of staff commitment, lack of resources, space and time. When improvements were not part of professionals' main roles or organizational priorities. <i>Conclusions:</i> The process of Experience-Based Co-Design (EBCD) provided opportunity for staff and patients to work together to identify and prioritize problems. A multipronged recruitment strategy is best. Take on only a couple priority projects at a time to ensure sufficient time and resources to work on them. Ongoing staff engagement is essential to ensure implementation of changes in the system. Equal relationships between staff and patients must be promoted.</p>
<p>Meyers, S., (2008, April). Take heed. How patient and family advisors can improve quality. <i>Trustee</i>. 14-22.</p>	<p>Case Report Article provides a narrative report on the experience of PFACs in hospitals in the USA. (n = 3)</p>	<p>Level V C</p>	<p><i>Key operating practices to make councils more effective:</i> Advisors are screened for their ability to see beyond a problem, work in a group, good judgment, ability to represent others, and problem solving skills. To ensure a diverse group consider race ethnicity, age, and employment background when screening advisors. Advisors participate in hospital orientation to ensure HIPPA compliance. Ensure endorsement of the PFAC by senior management to sustain changes and shape the organization. Make patient safety a regular agenda item for PFAC. Patients and families must be viewed as essential</p>

			<p>members of the health care team. Share progress of PFAC regularly with the leadership team to ensure that the work of the PFAC is disseminated and embraced across the program.</p> <p><i>Outcomes of PFAC:</i> Patient satisfaction scores climbed from 95% to 98%</p> <p>Drop in law suits since working more closely with patients and families</p> <p><i>Challenges:</i> More requests for advisors were had then they had advisors.</p> <p><i>Conclusions:</i> Hospitals can learn tremendous things by listening to their patients and families. PFACs are the wave of the future</p>
<p>Taloney, L., & Flores, G., (2013). Building Blocks for Successful Patient and Family Advisory Boards. Collaboration, communication and Commitment. <i>Nursing Administration Quarterly</i> 37(3), 247.</p>	<p>Expert Opinion Case Report</p> <p>Article provides a narrative report of PFAC implementation efforts in a hospital in the USA. (n=1)</p>	<p>Level V C</p>	<p><i>Key operating practices to make councils more effective:</i> the hospital must believe that patients and families are an integral part of health care and have important information to contribute.</p> <p>PFAC is chaired by a family member who meets with staff to develop the meeting agenda. PFAC meets once a month and lunch is provided.</p> <p>PFAC has participated in many hospital educational opportunities such as grand rounds, Lunch n Learns. Members must represent not only disease sites but geographic areas and cultural diversity of the population</p> <p><i>Outcomes of PFAC:</i> Advisors have contributed to many policies and procedures and have provided valuable feedback on many quality and safety projects. Hospital</p>

			<p>leaders, staff and physicians recognize that PFACs offer a voice to be heard <i>Challenges:</i> Not included <i>Conclusions:</i> Success of PFAC is due to administrative support and leadership from hospital leaders. The PFAC’s effectiveness and sustainability is related to the commitment of both families and leaders in the organization.</p>
<p>Warren, N., (2012). Involving Patient and Family Advisors in the Patient and Family-Centered Care Model</p>	<p>Expert Opinion</p> <p>An empirically based article drawing on the experience of healthcare facilities in both the USA and United Kingdom that utilize Patient and Family Advisors.</p> <p>Cites credible references</p>	<p>Level V B</p>	<p><i>Key Operating Practices to make councils more effective:</i> Chairs/Co-chairs must ensure that the meeting runs smoothly and remains focused. Meetings should be run formally with agendas and minutes Patients should be chosen for their ability to offer the generic patient voice. Use caution when selecting advisors to avoid those who have personal complaints or are too emotional to participate effectively in meetings. Support from the senior team is essential Recognize that experiential knowledge brings a unique and important perspective Begin with a well-defined project. Utilize a specific problem solving process like Plan Do, Study, Act. Have one staff member for every four advisors Anticipate challenges and barriers and identify ways to address them. Search out what financial backing is available <i>Outcomes of PFAC:</i> Organizations that are using</p>

			<p>patient and family advisors are reporting decreased length of stay, improved reimbursements and patient satisfaction.</p> <p><i>Challenges:</i> Some health care providers found working with patient and family advisors uncomfortable and thus hesitated to participate in open discussions regarding approaches to care. Fear of litigation was identified as a factor.</p> <p><i>Conclusions:</i> Patient and families are strong allies in performance improvement initiatives. Including patient and families encourages treatment of the whole person as they would want to be treated. Patients and families have shown healthcare teams that the journey toward patient centered care is most successful when taken together.</p>
<p>White, K., (2012) Engaging patients to improve the healthcare experience. <i>Healthcare Financial Management</i> 12 p. 84-88.</p>	<p>Case Study</p> <p>A case report on a group of American hospitals that implemented PFACs over 10 years ago.</p>	<p>Level V B</p>	<p><i>Key operating practices to make councils more effective :</i></p> <ul style="list-style-type: none"> Recruit appropriate patients. Create a strong infrastructure for the council. Ensure councils continue to have fresh input from new participants. Set clearly defined goals and implementation plans Measure the impact of the council <p><i>Outcomes:</i> Patient and family advisors have been instrumental in numerous projects and design improvements.</p> <p><i>Challenges:</i> Difficulty in measuring impact as councils</p>

			are a part of organization wide efforts. Ensuring that PFACs are not just a formality but an integrated and valued initiative <i>Conclusions:</i> PFACs require dedicated healthcare leaders and patients who are committed to active participation for the purpose of improving the patient experience.
Willis, R., Krichten, A., Eldredge, K & Carney, D., (2013). Creating a Patient and Family Advisory Council at a Level 1 Trauma Center. <i>Journal of Trauma Nursing 20(2)</i> p. 86-88.	Expert Opinion Case report An narrative article describing the process of implementing a PFAC in an American Level 1 trauma unit (n=1)	Level V B	<i>Key operating practices to make councils more effective:</i> Staff took the time to plan and recruit to PFAC. Patient and families make up the majority of the council. Patient and family members should have good communication skills, be comfortable working with others, embrace diversity, and be representative of the organizations’ consumers. Internal staff education was completed to explain the goals and purpose of the council as well as referral techniques. <i>Outcomes:</i> PFAC deemed extremely successful. PFAC members pleased with work done to address their concerns. <i>Challenges:</i> Recruiting patient and family members. Healthcare providers were viewed as hesitant to be vulnerable to opinions of patients and families <i>Conclusions:</i> The PFAC was considered constructive and complimentary
Zarubi, K. L., Reiley, P., McCarter, B., (2008). Putting patients and families at the Center of Care. <i>The Journal of</i>	Case Report An article describing how a Patient-family-	Level V B	<i>Key operating practices to make councils more effective:</i> Taking the time to do background work with healthcare leaders, managers

<p><i>Nursing Administration, 38(6), 275-281.</i></p>	<p>centered model of care including a PFAC was introduced and embraced in an American healthcare system (n=2)</p>	<p>and staff to help them gain a better understanding of PFCC and the benefits and challenges of partnering with patients and families on organizational issues. 1:1 ratio of patients and families and staff. Members asked to commit to 2 year term. Qualities of effective council members include: a positive approach, ability to share and see many different points of view, good listening skills, ability to share positive and negative experiences in a constructive way, ability to communicate with people with different backgrounds, experiences, and styles. Council co-chaired by staff member and patient/family rep. Meetings lasted 2 hours and opened with dinner. Involvement of the CNO was critical to ensure ongoing support and resources for PFAC initiatives. Blend of senior leaders, clinical leaders and frontline staff important to ensure communication of benefits of patient and family involvement throughout the organization. Link PFCC to patient safety, service improvement, and other priority initiatives</p> <p><i>Outcomes:</i> PFAC embraced by leaders and staff. Many other programs asked if they could seek the councils input. Trust developed between the organization and the council. Clinical programs have modified many policies and procedures to make them more patient and family centered.</p>
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