The 7th International Conference on Patient- and Family-Centered Care was held July 25-27, 2016, in New York City. Attended by over 1,000 individuals representing some 348 institutions and organizations from across the United States and around the world, the conference included 120 presentations and 89 posters on topics of patient- and family-centered care. A listing of all conference presentations is available online (http://www.ipfcc.org/events/conference-ny-syllabus.pdf) and materials from previous conferences are also available (http://www.ipfcc.org/events/past-conferences.html).

As the Institute for Patient- and Family-Centered Care (IPFCC) (see Figure 1) described in the conference syllabus/program book:

Collaboration with all stakeholders – patients, families, health care professionals, researchers, and educators is key. Together [these stakeholders] can best plan and put in to action policies, programs, and practices that address the significant challenges we face (IPFCC, 2016, p. 3).

To this end, over 165 patient/family advisors and leaders were presenters and co-presenters with over 285 healthcare professionals, researchers, and policy makers (R. Codling, Director Special Projects and Educational Programs, IPFCC, personal communication, August 1, 2016). Presentations and posters focused on expert experience as well as innovation in partnerships across the following key themes (http://www.ipfcc.org/events/conference.html):

- **Leadership Matters:** Exemplary national, provincial and state, and organizational leadership practices for advancing patient- and family-centered care resulting in widespread adoption and measurable change.
- **Patient and Family Advisors – Essential Allies:** Strategies, practices, and tools proven to be effective in expanding roles for patient and family advisors.
- **Better Together:** Changing the Concept of Families as ‘Visitors’: Initiatives taking a comprehensive and collaborative approach to change from restrictive policies and practices to welcoming family presence and participation.
- **Education for Interprofessional and Collaborative Practice:** Educational approaches, activities, and curriculum developed and conducted in partnership with patients and families.
- **Creating Capacity for Partnerships in Research:** Approaches or projects that reflect patient- and family-centered care planned and conducted in collaboration with patients and families, and expanding the knowledge base for patient-centered outcomes research.
- **Addressing Health Disparities:** Initiatives working in partnership with underserved communities to plan, implement, and evaluate programs that effectively reduce disparities in health care.

Learning objectives, detailed in Figure 2, further illustrate the wide range of topics addressed at the International Conference.

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**Figure 1.**

The Institute for Patient- and Family-Centered Care

Founded in 1992 as a nonprofit organization, the Institute for Patient- and Family-Centered Care (IPFCC) provides national and international leadership to advance the understanding and practice of patient- and family-centered care in all healthcare settings. IPFCC promotes partnerships among healthcare professionals, patients, and families to enhance policy and program planning, implementation, and evaluation; research; and education of healthcare professionals. IPFCC accomplishes its mission through education, consultation, and technical assistance; materials development and information dissemination; and strategic partnerships.

For information on upcoming IPFCC educational programming, visit http://www.ipfcc.org/events/seminars.html

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The *Family Matters* series focuses on issues, information, and strategies relevant to working with families of pediatric patients. To suggest topics, obtain author guidelines, or to submit queries or manuscripts, contact Co-Editors Elizabeth Ahmann, ScD, RN; or Deborah Dokken, MPA, *Pediatric Nursing*; East Holly Avenue/Box 56; Pitman, NJ 08071–0056; (856) 256–2300 or FAX (856) 589-7463.
Overview of Select Conference Presentations and Posters

One exciting, innovative direction in healthcare settings is partnering with patients and family members in the research process – not simply including them as subjects, but integrating them as advisors and participants in all stages of research, from topic identification, through study design, recruitment, data analysis, and interpretation, to choices about dissemination of findings. The topic of partnerships in research was addressed in a number of presentations at the conference and will be the focus of a future article in this series.

This article briefly highlights six other interesting innovations explored in IPFCC conference presentations and posters (see Tables 1 and 2), as well as identifies a variety of strategies that apply broadly when innovating around patient and family engagement. These strategies, highlighted below by six innovative programs engaging patients and family members, include:

- Assure a determined commitment to patient- and family-centered care (PFCC).
- Identify a champion or champions for the principles of PFCC and/or individual PFCC projects.
- Determine and address barriers.
- Involve stakeholders at every step of a project or program development.
- Delineate patient- and family-centered best practices and related benefits, value, and outcomes.

Source: Institute for Patient-and Family-Centered Care, 2016, p. 7.

Table 1. Select Conference Presentations

<table>
<thead>
<tr>
<th>Presentation</th>
<th>Presenters (Institutions)</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enacting Family-Centered Care in Situations of Required Social Separation</td>
<td>Rachel Biblow, LCSW, MSW, Senior Director, Patient and Family Services; Julia Sammons, MD, MSCE, Medical Director, Infection Prevention and Control; Amy Kratchman, BA, Family Consultant (The Children's Hospital of Philadelphia, Philadelphia, PA)</td>
<td>7/25/16</td>
</tr>
<tr>
<td>Harnessing Technology: Impact on Culture, Practice and Outcomes when Inpatients Have an Electronic Health Record/Portal in Their Hands</td>
<td>Michelle Lloyd, BSN, Vice President, Children's Services; Jacquelyn Fuller, BSN, Nurse Manager; Nancy Beale, BSN, MSN, RN-BC, Vice President, Clinical Systems and Integration; Kimberly Kilcoyne, BA, MS, Family Advisor and Family Faculty (Hassenfeld Children's Hospital of New York at NYU Langone, New York, NY)</td>
<td>7/25/16</td>
</tr>
<tr>
<td>Bridging the Disconnect: Empowering Advisors Through Social Media</td>
<td>Jessica Lamb, BSc, MScOT, Senior Patient Engagement Advisor, Strategic Clinical Networks, Alberta Health Services; Deb Runnals, RSW, Patient Advisor, Co-Chair, Patient First Steering Committee and Vice Chair, Provincial Patient and Family Advisory Group (Alberta Health Services, Calgary, Alberta)</td>
<td>7/26/16</td>
</tr>
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</table>

Table 2. Select Conference Posters

<table>
<thead>
<tr>
<th>Poster</th>
<th>Presenter(s)/(Institution)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family-Centered Collaborative Care for Children with Undiagnosed Complex Conditions</td>
<td>Angel Mitchell, CPN, MSN, RN, Nurse Coordinator, Declan Donoghue Collaborative Care Program; Nicole Donoghue (Brenner Children's Hospital of Wake Forest Baptist Health, Winston-Salem, NC)</td>
</tr>
<tr>
<td>Advancing Awareness of Young Adult Issues: Reviewing the Benefits and Deliverables Created by a Young Adult Advisory Council Following Implementation of a New Goal-Setting Model</td>
<td>Wendy Griffith, MSSW, Senior Social Work Counselor; Mark Gardner, BS, EIT, Member, Young Adult Advisory Council (MD Anderson Cancer Center, Houston, TX)</td>
</tr>
<tr>
<td>Children and Young People's Voices: Using Child-Friendly Surveys to Obtain Feedback from Young Inpatients to Move Toward Improving Patient-Centered Paediatric Care</td>
<td>Sarah-Ann Burger, MSc, Senior Project Manager (Picker Institute Europe, Oxford, United Kingdom)</td>
</tr>
</tbody>
</table>
• Engage patients and family members in roles allowing meaningful and significant contribution.

**Enacting Family-Centered Care in Situations Of Required Social Separation**

A presentation from the Children’s Hospital of Philadelphia (CHOP) highlighted the thoughtful process behind an unusual topic: hospital certification as a center for pediatric patients with Ebola.

This presentation, entitled “Enacting Family-Centered Care in Situations of Required Social Separation,” illustrated – while developing protocols ensuring safety through strict attention to infection control procedures – a commitment that PFCC would not be neglected in the process. Involving family advisors in the process of evaluating options, including participating in dry-run trials, assured that messaging to families and procedures for communication between parents and child, parents and care providers, including child life, and child, would be sensitive to child and family concerns. Specific details of strategies for maintaining PFCC if there was an Ebola break-out were interesting, but not the important lesson. What was important is the following take-away: a determined commitment to PFCC, combined with involvement of all key stakeholders in every step of planning, can make innovating around patient- and family-centered care effective, even in very challenging situations. This take-away message from the CHOP presentation was emphasized repeatedly in conference presentations.

**Harnessing Technology: Impact on Culture, Practice and Outcomes When Inpatients Have An Electronic Health Record/Portal in Their Hands**

Offering inpatients and their family members an electronic health record/portal – integrating inpatient, outpatient, and home care records – has many potential benefits, including improved patient and family access to information; improved communication, collaboration, and decision-making (i.e., PFCC partnerships); and improved safety.

When Hassenfeld Children’s Hospital of New York at NYU Langone Medical Center considered introducing an electronic health portal as an extension of the electronic health record for inpatients and their families, several barriers to implementation were identified. Not surprisingly, technological concerns were one issue, but other identified barriers were:

- From an institutional perspective, legal concerns related to family member access to teen records.
- From a family perspective, worry about both privacy and infection control related to using hospital-loaned devices.
- From a nursing perspective, concerns related to both maintaining a human touch in interactions and the time involved in introducing the devices to patients and family members.

Creatively addressing each of these concerns and involving patient- and family-advisors in the planning process led to piloting an electronic portal for inpatients and their families on one unit with the support of a champion nurse manager. As problems were worked out, the hospital plans to expand the program to other units.

This experience at Hassenfeld Children’s Hospital illustrates the importance of acknowledging barriers and involving key stakeholders in order to address barriers, identifying ways to move forward with patient- and family-centered initiatives. The experience also demonstrates that passionate, committed champions for PFCC are an essential ingredient in developing momentum, that, once established, can lead – sometimes through pilot projects designed to work out various “kinks” in a new idea – to eventual enthusiastic adoption of a new process or program furthering PFCC.

**Bridging the Disconnect: Empowering Advisors Through Social Media**

Alberta is a very large Canadian province, and thus, is served by a single provincial health care system – Alberta Health Services (AHS). Patient and family advisors in the Alberta Strategic Clinical Networks (SCN) are widely spread geographically. At the 2014 Provincial Patient and Family Advisor Conference, these advisors raised concerns about “feeling isolated and disconnected from each other” (Wong & Lamb, n.d.). To explore ways to address these concerns, a survey was conducted among some 500 AHS patient and family advisors and patient and community engagement researchers, with 52% rating social media as a possible way to connect.

Presenters from AHS described institutional concerns rising to the fore about using social media in relating with patient and family advisors. An institutional suggestion was made to instead send out periodic email communications to advisors. However, the use of large group email bulletin boards is a one-way communication that neither builds a connection nor decreases a sense of isolation, and is not fundamentally patient- and family-centered. A family advisor stepped forward to partner with an SCN patient engagement specialist, and both committed champions of PFCC, creatively pushed ahead, after identifying a significant barrier, in working with patient and family advisors, in developing an organization outside of the hospital that would experiment with using social media to link patient and family advisors, as well as obtain their input on issues.

Institutional attitudes began to shift as these tools become a rich approach, allowing for surveys, discussion, and importantly, building a sense of community among patient and family advisors. AHS has subsequently embraced the use of social media as a way to communicate with, learn from, and develop partnerships with advisors. More importantly, using social media has directly connected patient and family advisors, empowering them to become more effective change agents, benefitting patients, families, and AHS as a whole. As one advisor explained: “We are the most effective as advisors when we are no longer isolated. When we can connect, we feel supported as a community and can bring the best patient voice forward” (Wong & Lamb, n.d.).

**Family-Centered Collaborative Care for Children With Undiagnosed Complex Conditions**

Often, children with complex conditions see numerous specialists who may not always communicate with each other. Additionally, these children may not have a primary care provider or any other professional who coordinates care or directs the process of diagnosing a complex or rare condition. In these circumstances, parents, in addition to parenting and providing specialized care, can find themselves in the confusing and fatiguing position of trying, sometimes over long periods of time, to get answers that make sense of symptoms, lab work, and the impressions of numerous specialists.

The poster “Family-Centered Collaborative Care for
Children with Undiagnosed Complex Conditions” from the Brenner Children’s Hospital of Wake Forest Baptist Medical Center highlights a family-initiated innovation related to diagnosis of children with complex conditions. In this situation, the parents of a child whose rare condition was diagnosed only through an autopsy after death approached Brenner Children’s Hospital, determined to save others the pain of their own family’s loss. They suggested the need to provide families with both support and coordination in finding answers and uncovering diagnoses. The Declan Donoghue Collaborative Care Program was developed to address an enormous barrier in the care of children with undiagnosed complex conditions and their families, demonstrating what can happen when a healthcare setting welcomes the meaningful and significant contribution of parents, true champions in this and many instances.

Advancing Awareness of Young Adult Issues: Reviewing the Benefits and Deliverables Created by a Young Adult Advisory Council Following Implementation of a New Goal-Setting Model

Many posters and presentations at the IPFCC Conference addressed either adult patient and family member engagement or parent and other family member engagement in pediatric settings. However, approaches to involving young people themselves in patient advisory roles were far fewer.

As described in the conference program book, the poster “Advancing Awareness” from the MD Anderson Cancer Center in Houston reviewed “the positive outcomes and interprofessional educational curricula that resulted following the implementation of a new structure and goal-setting model within an oncology young adult advisory council” (IPFCC, 2016, p. 71). Council members collaborated to create new educational materials, increasing awareness of young adult needs and resources among MD Anderson employees and community members, including young adults. As a result, needs of young adult patients are being more effectively identified and addressed, improving both perceived quality of care, and more importantly, quality of life (W. Griffith, Senior Social Work Counselor, MD Anderson Cancer Center, personal communication, August 2, 2016). This poster emphasized a theme raised in a number of conference presentations: provide opportunities for patient (and family) engagement in roles allowing meaningful and significant contribution.

Children and Young People’s Voices: Using Child-Friendly Surveys to Obtain Feedback from Young Inpatients to Move Toward Improving Patient-Centered Paediatric Care

Increasingly, parents, and in some cases, teens and young adults, are engaged in the design and provision of systems of care and the development and introduction of patient- and family-centered innovations in pediatric settings. It can be difficult, however, to imagine how younger children can be effective participants in the design of systems of care that serve them. One reason, of course, is that other than anecdotal approaches, “[f]ew tools exist to robustly measure children and young people’s experience of healthcare” (IPFCC, 2016, p. 73). Yet the voices and views of children are important to truly deliver patient-centered care.

The poster “Children and Young People’s Voices” from the Picker Institute Europe focused on “using a tested, age-appropriate tool, and present[ing] results of 70 NHS trusts who participated in a national children’s inpatient and day care survey” in the United Kingdom (IPFCC, 2016, p. 73). A report on how data were used by one hospital to shape and improve services was published in Health Service Journal, March 9, 2016. Gathering data directly from children is the first step in engaging the most important stakeholders in examining and improving the care they receive. As the poster stated: “Focusing on improving the aspects of their care that are most important to children, you can make the biggest difference to patient-centered care in paediatric settings” (Burger, 2016).

References