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### **FAMILY CENTRED CARE**

Developed by Rachel Goren and Dr. Eyal Cohen for PedsCases.com. Sept 12, 2024.

### Introduction:

Hello, and welcome to the PedsCases podcast on an approach to Family Centred care! My name is Rachel Goren and I am a fourth year medical student at Queens University in Kingston Ontario. This podcast is designed to give medical students an understanding and approach to family centred care. This podcast was developed in collaboration with Dr. Eyal Cohen, Staff Pediatrician at the Hospital for Sick Children and the University of Toronto.

After listening to this podcast, you should be able to

- 1. Define family-centered care and its importance in healthcare.
- 2. Identify key principles of family-centered care.
- 3. Describe strategies to implement family-centered care in clinical practice.
- 4. Discuss the benefits and challenges of family-centered care.

Before we dive into the core content, let's consider a clinical scenario to set the stage for our discussion. As we progress through the objectives, we will revisit this scenario to see how family-centered care principles can be applied.

## **Clinical Case**

Meet Mia, a 5-year-old girl admitted to the pediatric ward due to an asthma exacerbation secondary to a viral illness. Mia's parents, Mark and Lisa, have brought her to the hospital with a 24 hour history of worsening shortness of breath and wheezing. Mark works as a teacher, while Lisa manages a small catering business from home. This is Mia's first presentation with asthma, and they are deeply concerned about her respiratory distress. Mark and Lisa are eager to learn more about asthma, including its treatment options, potential complications, and how they can support Mia's recovery at home. They have expressed a strong desire to actively participate in Mia's care and decision-making process

## **Definitions and Importance**

Developed by Rachel Goren and Dr. Eyal Cohen for PedsCases.com. March 10th, 2025

Family-centered care is a collaborative healthcare approach that acknowledges the crucial role of both family and patient in the care process. It emphasizes collaboration between healthcare providers, patients, and families to ensure that care is respectful, responsive, and tailored to the needs and preferences of the patient and their family.

Research has shown that family-centered care can lead to improved health outcomes, higher patient and family satisfaction, and better adherence to treatment plans. It is especially crucial in pediatrics, where involving the family can significantly impact the child's well-being and recovery.

# **Principles of Family-Centered Care**

There are four core principles of family-centered care:

- 1. Dignity and Respect: Healthcare providers should treat patients and their families with empathy and respect, acknowledging their concerns and validating their emotions. This approach involves understanding their cultural background and personal beliefs, which are crucial in tailoring treatment plans and building trust.
- 2. Information Sharing: Healthcare providers should communicate clearly and effectively, using simple, jargon-free language. Sharing complete and unbiased information allows families to be well-informed and actively involved in care decisions. Educational materials should be accessible and relevant to the family's level of understanding.
- 3. Participation: Patients and families should be encouraged and supported in participating in care and decision-making at the level they choose. Empowering them to share observations about symptoms and responses to treatment ensures their insights are valued and incorporated into the care plan. By actively including the child in discussions and decision-making when appropriate, we ensure that family-centered care remains true to its core purpose: providing the best possible care for the patient while respecting the integral role of the family unit!

Children of all ages can and should be involved in their care process. For example:

- With toddlers, offering simple choices can foster engagement. A healthcare provider might ask, "Which ear should I look in first?" when performing an otoscopic exam.
- For school-aged children, healthcare providers can directly engage patient's about their symptoms. A provider might ask, "How has your breathing been lately? Are there times when it's harder to breathe?" This approach involves the child in their care, encourages self-reflection, and gathers valuable clinical information while making the child feel respected and heard.
- For adolescents, healthcare providers must offer opportunities for confidential conversations about their health concerns and involve them in decisions about their treatment, respecting their growing independence and right to participate in their own care.



4. Collaboration: Foster a collaborative partnership by inviting families to participate in daily rounds and decision-making processes. This approach ensures that the family's input is respected and integrated, leading to better care outcomes and satisfaction.

## Strategies for Implementation

Implementing family-centered care involves deliberate strategies to foster collaboration and engagement between healthcare providers, patients, and families. These strategies are essential for ensuring that care is respectful, responsive, and tailored to meet the unique needs of each patient and their family.

- 1. Open Communication: Establishing open lines of communication is foundational to family-centered care. Healthcare providers must communicate in a clear, compassionate manner, ensuring that information is shared comprehensively and in a way that families can easily understand. This involves providing verbal updates and utilizing written materials such as educational handouts and visual aids. Additionally, offering interpretation services ensures that communication remains inclusive and accessible to all families, regardless of preferred language.
- 2. Family Involvement: Actively involving families in care planning and decision-making empowers them to contribute meaningfully to their loved one's healthcare journey. Encouraging families to participate in family meetings, care conferences, and bedside rounds facilitates collaborative decision-making with healthcare teams. Tools such as decision aids help families navigate complex medical choices, while designated family spaces within healthcare facilities ensure privacy and encourage open discussion.
- 3. Education and Support: Providing comprehensive education equips families with the knowledge and skills needed to care for their loved ones effectively. Healthcare providers should offer tailored education sessions that address the specific needs of each family, utilizing technology such as educational videos or telehealth platforms for remote access. Training on medical procedures and self-care techniques enables families to confidently manage their loved one's condition at home. Emotional support resources, including counseling services and community referrals, help families cope with the emotional challenges of caregiving.
- 4. Feedback Mechanisms: Establishing effective feedback mechanisms enables families to share their experiences and suggestions for improving care. Healthcare providers should implement structured feedback avenues, such as surveys or digital platforms, to solicit family perspectives regularly. Real-time feedback systems allow families to provide input instantly, promoting timely adjustments to care practices. Healthcare teams should prioritize incorporating family feedback into quality improvement initiatives to enhance care delivery and patient outcomes.

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# **Benefits and Challenges**

Family-centered care offers numerous benefits that contribute to improved healthcare outcomes and patient experience. By emphasizing **dignity and respect**, family-centered care enhances patient and family satisfaction by actively involving families like Mark and Lisa in decision-making and care processes.. Research consistently shows that when patients and families are engaged, they feel more informed, empowered, and satisfied with care. This involvement fosters trust and collaboration between healthcare providers and patients/families, leading to a more positive overall healthcare experience.

Moreover, family-centered care significantly enhances patient safety. By sharing information effectively, families, serve as vigilant partners in monitoring their loved one's condition, identifying potential risks, and ensuring adherence to treatment plans. This collaborative approach reduces the likelihood of medical errors and contributes to better patient outcomes.

The implementation of family-centered care is associated with improved health outcomes. Studies demonstrate when families **participate** in care decisions that there is reduced hospital readmissions, improved medication adherence, and better management of chronic conditions. This is particularly crucial in pediatric care, where family support plays a pivotal role in a child's recovery and overall well-being.

However, despite these significant benefits, several challenges hinder the widespread adoption of family-centered care in healthcare settings. One major obstacle is the perception of time constraints among healthcare providers. Engaging families requires additional time for discussions, education, and addressing concerns, which can be challenging in busy clinical environments. Healthcare institutions need to prioritize strategies that streamline family involvement without compromising the efficiency of care delivery.

Another critical challenge is resistance to change within healthcare culture. Traditional models often prioritize provider-driven decision-making over **collaborative** approaches that include families. Overcoming this resistance involves comprehensive training programs that equip healthcare providers with communication skills and strategies for integrating family-centered care into their practice. By fostering a culture that values and supports family engagement, healthcare organizations can facilitate smoother transitions towards patient- and family-centered care models.

Additionally, resource limitations pose a significant barrier to implementing family-centered care effectively. Institutions must allocate resources for staff training, support services for families, and infrastructure enhancements that facilitate family involvement. Investing in these resources is essential for ensuring that families receive comprehensive support and that healthcare providers have the necessary tools to deliver patient-centered care.



Let's tailor the family-centered care principles to Mia's clinical scenario!

**Dignity and Respect:** When approaching Mia's room, you start by knocking on the door to signal your respect for their space. Upon entering, you greet Mia first with a warm smile, followed by her parents, Mark and Lisa. You say, "hi Mia, it's nice to meet you! Hello Mark and Lisa, I'm Rachel Goren, a third-year medical student." You make sure to introduce yourself clearly, ensuring your name is memorable and inviting them to use it. You acknowledge their concerns by saying something like, "I understand this is Mia's first asthma exacerbation, and it must be quite worrying for you both." This approach validates their emotions and helps build trust. Additionally, you take the time to understand their cultural background and personal beliefs, which can be crucial in tailoring Mia's treatment plan. For instance, asking, are there any cultural practices or family traditions we should consider in Mia's care?" demonstrating your respect and willingness to collaborate.

Information Sharing: You communicate with Mark and Lisa using simple, jargon-free language. For example, you might say, "Asthma can cause the airways in the lungs to become inflamed, making it hard for Mia to breathe. We'll work together to manage this." You provide educational materials, such as pamphlets or videos about asthma management, and ask them how they prefer to receive information. You ask "would you prefer updates through in-person meetings, or do you find written summaries more helpful?" You also talk with them early on about how often and in what ways you usually provide and can provide information. Ask them if they'd like you to share what you're learning and considering as you proceed through the diagnostic process, or if they'd prefer to receive information in larger chunks only after the whole picture is much clearer. You explain the diagnostic process and your role clearly: "As a medical student, I'll ask some questions about Mia's symptoms, check her vital signs, and then discuss my findings with the attending physician."

Participation: To foster active participation in Mia's care, you engage both her parents and Mia herself! Begin by addressing Mia directly: "Mia, how are you feeling today?" This approach acknowledges her as the primary patient and encourages her involvement in her own care. Then, turn to Mark and Lisa: "What are your main concerns about Mia's condition." Empower the family to share observations: "Have you noticed any changes in Mia's breathing patterns or her response to medications?" Inquire about their priorities: "To support Mia effectively, it would be helpful to know what aspects of her care are most important to you as a family. What are your goals for Mia's treatment?"

Encourage age-appropriate involvement from Mia: "Mia, is there anything you'd like to ask about your asthma or the treatment plan?"

By integrating Mia's voice and her parents' concerns, you create a comprehensive care approach that respects the child's autonomy while valuing the family's input. This

method ensures that all perspectives are considered, leading to a more effective and personalized treatment plan.

**Collaboration:** You encourage Mark and Lisa to join daily family-centered rounds, where the healthcare team discusses Mia's care goals and addresses questions. You might say, "We invite you to join us each morning for family-centered rounds to review Mia's progress and set goals for the day." It is important to be flexible if caregivers are unable to attend family morning rounds due to other commitments such as work and child care. If this is the case, ask caregivers how and when they would like to be contacted to discuss a collaborative plan for their child.

**Emotional Support:** You recognize the emotional challenges Mark and Lisa might face and offer resources such as counseling services or support groups. For instance, you might say, "We have a support group for parents of children with asthma that meets weekly. Would you be interested in joining?" You allow them time to respond to your questions and formulate their own response, being comfortable with silence. This can be as simple as saying, "Take your time; I'm here to listen to any questions or concerns you might have."

**Inclusive Language:** Ensure that all communications and interactions with Mia, Mark and Lisa are culturally sensitive and inclusive. Recognize and respect their diverse cultural backgrounds and beliefs, fostering a trusting relationship and mutual understanding. This inclusive approach creates a supportive environment where Mark and Lisa feel valued and heard in Mia's care journey.

#### Conclusion

By consistently applying these family-centered care principles—dignity and respect, information sharing, participation, collaboration, and emotional support—healthcare providers can create a supportive environment that empowers families like Mark and Lisa's to actively participate in Mia's care journey. This approach not only enhances Mia's medical outcomes but also strengthens the partnership between healthcare providers and families, ultimately improving the overall care experience and satisfaction.

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