FAMILY-CENTERED CARE OF CHILDREN AND ADOLESCENTS pdf

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Open and objective communication and information sharing Information sharing: Ideally, the principles drive our understanding of essential FCC practices, but this is not always so, as we will discuss further. The Institute of Medicine recognizes patient-centered care as one of the 6 central aims for high quality health care, and in , the Patient-Centered Medical Home was affirmed by multiple groups as the standard of health delivery [16]. However, we believe FCC is the term of choice as it relates to pediatric care, when families are most involved with their children. FCC moves beyond patient-clinician interaction by considering the needs of all family members, not just the child [18]. How Did We Get Here? Families in the hospital setting were relegated to a visitor or attendant role [11]. In parallel, families of children with intellectual impairments were encouraged to institutionalize their children at facilities such as the Experimental School for Teaching and Training Idiotic Children in Massachusetts [20]. Hospital inpatient rounds, which had moved away from the bedside and to the conference room [21], began to move back towards the bedside [22]. Family advocates played a large role in changing hospital-based care for children and their families, just as they were central to the process of promoting the deinstitutionalization of children with intellectual and other disabilities in their communities [23]. Family advocates were essential to the passage of the first special education law P. Family advocacy for children with special needs subsequently extended into the health care policy arena. With the backing of family advocates, the MCHB and the US Surgeon General sponsored several national conferences on children with special health care needs in the mids [24]. In the MCHB changed its mission to read: Starting in the s, the MCHB supported medical home learning collaboratives and the national grassroots family network, Family Voices, leading to family-to-family health information centers in every state. Where Are We Now? Implementation, advocacy, and policy of FCC can be grouped into two settings: With different origins, operationalizing FCC in different settings has not always resulted in similar applications and outcomes within the inpatient and ambulatory settings. Family presence alone is considered insufficient, as family members must participate in the discussion and decision-making; at its best, the presence and participation of families promotes the FCC principles of Information Sharing, Partnership and Collaboration, and Negotiation. Almost one-half of pediatric hospital medicine groups now use FCR [34]. FCR is also regarded as an important component of medical education. Some hospital systems also incorporate families at different levels of clinical care and education on a formal, systematic basis. Hospitals that incorporate experienced family leaders as peer consultants or staff generally have already existing successful family advisory boards or peer support groups. The Ambulatory Setting In contrast to the inpatient setting, ambulatory encounters have no accepted, well-developed intervention such as bedside rounds in the inpatient setting. Accordingly, the inpatient setting tends to lead development of FCC initiatives [42 , 43]. However, FCC is recognized as the standard of care in all ambulatory settings, including primary care [44], specialty care [7], emergency care [45], and chronic care [46]. This recognition has led to much discussion about FCC, but fewer concrete initiatives, particularly when compared to the inpatient setting. Operationalizing FCC in the ambulatory setting revolves around the Medical Home concept, which specifies that care for all children should be accessible, coordinated, comprehensive, family-centered, culturally competent, continuous, and compassionate [14]. The roots of the Medical Home lie in improving care for CSHCN [27], which may explain why so many tenets appear to focus on the child with special needs. However, FCC principles in the ambulatory setting are often described in terms of individual encounters. Recommended FCC practices in the emergency room address patient flow, assuring family presence, providing care coordination, and improving communication [45]. Specific actions or training that operationalize these principles are less well-described; a blueprint that led to negotiation in a situation like our sample case report, Adam and his family, is not part of the recommended FCC practices. Also less described is how FCC principles translate into optimal longitudinal care [14 , 44]. The simple act of maintaining continuity of care, highly valued by families [48], is associated with optimal ambulatory care

outcomes [49 â€" 51] and may serve as the foundation of longitudinal family-centered care. Family roles and needs evolve during a relationship, particularly in chronic care as the family becomes increasingly educated about a condition [52]. Over time, family trust of the provider may wax and wane [53], but little guidance exists to consistently improve and practice trust, partnership, and FCC. Other FCC ambulatory practices are directed towards non-encounter, primary care-based services that address identified family needs. Examples include care coordination with subspecialists and community-based services [54 , 55], family education and assistance [56 , 57], and the use of parent advisers in quality improvement initiatives [58]. Similar practices have been reported in subspecialty fields, such as child development and rehabilitation medicine [7]. Grass-roots, family-led groups such as Family Voices and the Institute for Patient- and Family-Centered Care formerly the Institute for Family-Centered Care have developed several ambulatory initiatives. Education and resources are achieved through one-on-one counseling, conferences, and direct training seminars [59]. Evidence suggests, however, that family needs are frequently not met in the ambulatory setting. In primary care, many families report not discussing desired topics on development and behavior [60 â€" 62]. Families of children with chronic or complex conditions report multiple unmet needs on information and physician collaboration [9 , 10], specifically on community services, condition understanding, and networking [63 , 64]. Families and physicians often have different expectations about how families can best be assisted [63]. Cultural differences may account for additional variation, particularly from immigrant families with different medical experiences [65 , 66]. Does Family-Centered Care Help? Current Evidence While seemingly intuitive that addressing family needs improves health care and outcomes, the evidence to support this is surprisingly scant. High quality evidence is necessary to drive changes in the health care system and policies that facilitate the practices that have been presented. Limitations include a paucity of studies that isolated family-centeredness within a broader study, the lack of clarity of how FCC is operationalized, and most importantly, the absence of studies that include all the principles of FCC. On the inpatient side, families specify that rounds are better when a nurse is present, when the family is introduced and involved in the discussion, and when medical terminology is avoided or interpreted [22 , 28 , 30 , 31 , 33 , 35 , 69]. Despite the scarcity of accepted FCR measures, studies report that FCR may increase family understanding and sharing in decision-making, and their sense of respect from the medical team [22 , 35 , 38 , 69 , 70]. Additional reviews suggest benefits from family-centered interventions. Patient-focused interventions support health literacy and self-management [71], and consumer involvement results in relevant information gain [72]. One review found that patient-centered care may lead to empowerment and improved self-management [5]. Two additional studies found that such an approach may translate into improved child health and behavior [73 , 74]. We feel that there are 3 main barriers to FCC: Understanding Family-Centered Care Ambiguity remains on what specific actions constitute FCC, on both the level of provider and patient. Some providers consider FCC as delegating more responsibility to families for care and decision making than families desire [9 , 10]. In addition, focusing on encounter-based provider behavior does not always address the context of the community and the system of care. Families do express a desire for partnership and joint decision-making and not necessarily increased responsibility and autonomy [75]. However, families also may not understand what they can and should expect in a partnership. Parents consistently rate high levels of satisfaction with a sense of partnership in a variety of child health care settings [76 â€" 78], even as subjective descriptions of care are far less satisfactory [9 , 10]. This discrepancy may reflect a ceiling effect of expectations; many parents may not know they can expect care, information, and decision-making on shared terms. Support for Practices Barriers to substantive partnering include inadequate or changing insurance coverage, and family financial difficulties and employment constraints [79]. These barriers erode continuity of care that comprises the base of FCC. Considerable time and repeated visits with providers may be needed to build family support and partnering [68 , 80 , 81]. Reimbursement policies do not adequately support physician time and effort required to develop partnerships [80 , 82 , 83] putting motivated practitioners at risk for diminished reimbursement. Research Research is hampered by a lack of true validated measures and outcome measures for FCC. The lack of adequate research has been noted previously [84]. Measures that assess family impressions of care fall short in correlating specific actions with overall health and outcomes. The Measure of

Processes of Care, a scale developed in the s that evaluates the family-centeredness of services, has been largely used only for children with neurodevelopment conditions [85]. An index of family-centeredness based on the Consumer Assessment of Healthcare Providers and Systems survey has been used in national surveys [86 , 87]. This tool asks providers to reflect on the family centeredness of care and ways to improve that care [89]. Moving Forward The advance of inpatient care demonstrates that transformation to a fully family-centered system of care can begin with small changes. However, system-level changes must occur to enable providers and families to engage in information-sharing and decision-making, creating the partnership that leads to improved outcomes. The principles of FCC should be acknowledged and actively incorporated within all clinical care delivery and practice guidelines. Where evidence exists, recognized FCC care practices should be followed. Where no evidence exists, particularly in the ambulatory setting, families and providers should lead and champion care delivery redesign that considers the needs of families [7]. Examples include shared decision making, trained language interpreter services, open scheduling, and families as partners in policy-making and facility redesign. FCC principles are best learned through daily exposure and practice. Language should be respectful, care plans should be made jointly, and clinical decisions should consider the context of the family and community. These recommendations particularly apply to educators. As the current generation of trainees is taught the principles of FCC, learns the skills and ethics required, and experiences the benefits, the system will be more quickly impacted as this generation moves into practice and positions of leadership. Specific FCC practices, such as family presence at bedside rounds or procedures, should be implemented and evaluated as part of quality improvement projects. Such practices should be linked with measurable, controlled outcomes. Measurement and evaluation tools for FCC should be developed and validated. The tools should have high enough standards that are linked to positive health outcomes and not only to parent satisfaction. Appropriate process measures may include family input, provider name recognition by families, and reduction of unmet needs. Research should examine expectations for long-term health care savings, contributions to society, improvements in health and quality of life, and patient satisfaction. All may be acceptable in lieu of short-term cost neutrality or savings. Institutions should be familiar with all FCC principles and integrate families in high-level planning and design before the FCC label is applied to any health care initiative or process. FCC is a continuum of provider partnership and behavior. Accordingly, we cannot at this time recommend a threshold for when the FCC label is used by governing bodies or public relations. Increases in external resources for care reform and system changes, specifically targeting FCC, should be offered. Ongoing education of legislators, policymakers, and funding agencies should raise awareness of the short- and long-term value of FCC as the standard for clinical care and within health care systems. Providers can team with family advocacy groups to advance the importance of FCC education and research. Payment and reimbursement policies should recognize the time necessary to engage in FCC. Examples include the time needed for information sharing through counseling in-person or on the phone, care coordination, and other areas of family support.

2: Family-Centered Care: Current Applications and Future Directions in Pediatric Health Care

*Family Centred Care of Children and Adolescents: Nursing Concepts in Child Health [Jo Joyce Marie Tackett, Mabel Hunsberger] on www.enganchecubano.com *FREE* shipping on qualifying offers.*

RCH will foster a culture of participation in its internal and external communities in accord with Victorian Government commitment in this area. RCH will aim to facilitate the involvement of children and adolescents in their healthcare according to their maturity, age and any relevant law. There is increasing evidence that participation in health leads to better outcomes and better quality of care. In the context of this document, consumer means patient. Children and adolescents at RCH are current or potential users of the health care service, either directly or indirectly. It includes children and adolescents living with a disability, those from diverse cultural and religious backgrounds, and with varying social circumstances, sexual orientations, health and illness conditions. Family - the patient, their carers and relatives. The members of the family are determined by the patient and their carers and sometimes include close friends. In the context of RCH, the word family replaces carer and is defined as people who provide support to children requiring the services of RCH, be it directly or indirectly. Family may include parents, siblings, other relatives, guardians or friends. If the child is capable, family is who the child defines it to be. A group of people who have characteristics in common. For example, groups with the same health condition or disease, support groups with a common interest or ideology, groups from a similar ethnic or cultural background, groups from a specific geographical location or catchment. The population that RCH serves is made of many diverse communities. Child, Adolescents, Family and Community participation: The process of actively involving children, adolescents, families and communities in their own health care and in health service planning and priority setting; policy development, implementation and evaluation; resource allocation and quality improvement initiatives. Diversity This is a broad concept that includes all Australians. Recognising that each person is a unique and complex being is integral to understanding and responding effectively to health care needs at an individual, family or community level. Diversity refers to age, personal and professional background, education, function and personality. It includes lifestyle, socio-economic status, sexual preference, ethnicity and status within the general community. Facilitating access for these often marginalized groups and individuals must occur across all areas of healthcare. Procedure details This procedure is divided into four sections: Principles Caring for patients together - how we care for patients, for example during inpatient and outpatient stays Improving the hospital together - how to make the hospital more patient and family centered Managing the hospital together - how we involve families in hospital management Principles Zero Harm Quality and Safety â€" improve the quality and safety outcomes and the experience of care by encouraging and supporting patients and families to be actively involved in their treatment and care. Dignity and Respect- Health care practitioners listen to and honour patient and family perspectives and choices. Patient and family developmental needs, knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care. Information Sharing- Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making. Participation- Patients and families are encouraged and supported in participating in care and decision-making at the level they choose. Collaboration- Patients, families, health care practitioners, and leaders collaborate in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care. Caring for patients together The capacity and ability of patients to participate in their health care will vary on the basis of factors such as developmental level, culture and personal choice. Patients and families will vary in their requirements for information, decision making and involvement. Patients may or may not wish to participate. RCH will explore this choice and respect their wishes. Evidence has shown that patient and family centered care can produce benefits such as: Treat patients and families with dignity and respect: Improving the hospital together Involving patients and their families on specific issues or projects. Our role is to provide safe, quality care and services to patients and their family They perceive what

we do differently from us, so can give us a different view about what we do, how we do it and how we can improve Who? Who are the right people to ask for what you are trying to find out about? Ask as soon as possible after the experience e. Surveys, interviews, focus groups, complaints, feedback forms are common ways to seek information. Some other techniques to consider are:

3: Policies and Procedures : Patient and Family Centred Care

Family-centered care emerged as an important concept in health care the second half of the 20th century, at a time of increasing awareness of the importance of meeting the psychosocial and developmental needs of children and of the role of families in promoting the health and well-being of their children. Family-centered care has long.

This article has been cited by other articles in PMC. Abstract Background Responsibility for diabetes management tasks must shift from caregivers to adolescents as adolescents grow older. Also, family-centered care is a way to provide efficient care for them at home. This study aimed to identify the effect of family-centered care on management of blood glucose levels in adolescents with type 1 diabetes mellitus T1DM. Methods This is a Pre-experimental study with a pre- and post-test design. The participants consisted of forty adolescents with T1DM, aged between years, with their caregivers who were selected through simple random sampling from Hamadan Diabetes Research Center in Iran in The sample was divided into four similar groups. Educational sessions were conducted for each group for 30 to 40 minutes. Therefore, Family-centered care could provide for better regime adherence at home. Adolescent, Diabetes Mellitus Type 1, Family Introduction Diabetes mellitus is a serious disease with potentially devastating complications and is common among all age groups worldwide. Its prevalence in school-age children is 1. In the United States, one out of every children and adolescents has diabetes. Medical costs for people with diabetes are two to three times higher than non-diabetics. If diabetes is not controlled properly, vascular changes will occur in less than 3 years after diagnosis; however, adequate control can postpone these changes for up to 20 years and even more. Other serious physical complications include visual, renal, cardio-vascular and neural disorders, which can result in blindness, severe kidney failure, heart or stroke attack and amputation. However, for children of all ages, it is a difficult and tedious process and the close and direct supervision of the family is required. Sometimes, the onset of juvenile diabetes is between years. Family-centered care, as one of the main concepts of pediatric nursing, emphasizes support, increasing the knowledge of parents and children and the continuity of care for children with special needs. Prevention is an important component of the treatment paradigm, because tight glycemic control delays the onset and progression of complications of insulin-dependent diabetes mellitus IDDM. Therefore, they and their families will require continuing and lifelong education and training. Since we intended to examine cross-sectional associations between responsibility sharing, diabetes management, and glycemic control in adolescents with type 1 diabetes and their caregivers, we hypothesized that more caregiver responsibility would correlate with more frequent diabetes management and lower A1c values. Materials and Methods This Pre-experimental study had a pre- and post-test single-group design, and was conducted between February and June The sample size was estimated based on the study of Rezai et al. Thirty-seven adolescents were to be selected, but with regard to the risk of loss, 40 adolescents aged between 10 and 14 years together with their caregivers were selected through the simple random sampling method.

4: Home Care Services

Note: Citations are based on reference standards. However, formatting rules can vary widely between applications and fields of interest or study. The specific requirements or preferences of your reviewing publisher, classroom teacher, institution or organization should be applied.

5: Family-Centered Care | Children's Hospital Pittsburgh

Family-centered care is commonly used to describe optimal health care as experienced by families. The term is frequently accompanied by terms such as "partnership," "collaboration," and families as "experts" to describe the process of care delivery [2,].

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