
بسم الله الرحمن الرحیم


لله نور السموات والارض

مراقبت های تسکینی خانواده محور

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Importance of Family-Centered Care to Palliative Medicine

- **The family** is inevitably involved in care-provision when one of its number suffers from a progressive and life-threatening illness such as advanced cancer.

Importance of Family-Centered Care to Palliative Medicine

- Distress reverberates throughout the family, with moderate rates of psycho-social morbidity, including up to one third of partners and one quarter of adult children .

- There has been growing awareness over recent years of the importance of a family-centered model of care to fully meet the needs of patients and families involved with palliative care services and, moreover, maintain continuity of support into bereavement .

Importance of Family-Centered Care to Palliative Medicine

- To achieve this, we need both conceptual and pragmatic methods of classifying families to guide our efforts at intervention.

- Historically, one approach has been:
  - to conceptualize families in terms of the phase of illness they must negotiate;
  - another stressed the family's needs or the associated burdens it experienced;
  - a third focused on the family's developmental stage.

- Yet none of these approaches proved predictive of psycho-social outcome over time.

- It was not until attention turned to family functioning that a clinically useful method of predicting psychosocial outcome emerged .

What is family in palliative care?

Families of patients receiving palliative care are profoundly affected by **the challenges of the illness.**

- They observe care that the patient receives,
- provide care for the patient, and
- receive support from health professionals in the form of ***information, counselling, or practical assistance.***

Why is family important in palliative care?

Early family meetings may help patients and families:

- engage with advance care planning,
- make careful goal-centered treatment decisions, and
- take care of important medico-legal decisions, such as creating a will.

What is the role of family in the palliative care setting?

- Palliative care is patient and family centered care.
- The illness affects both patient and family, and patient and family characteristics affect the illness.
- Geographic and cultural factors influence who is considered as family and what is expected from them in the setting of illness.

What Is Family-Centered Care?

Family-centered care takes a holistic approach to patient care.

- The shifting from client-centeredness to family-centeredness in the care is initiated by the recognition of the significance of treating the patient in the context of the family. 1

In this care delivery method, the health care professional, the patient, and the patient's family ***establish a partnership*** that becomes the foundation for the planning, delivery, and assessment of the patient's care.

This partnership allows a family-driven perspective to influence the patient's care, as it ensures that health care professionals acknowledge the family's central function in caregiving and advocacy.

1.Bamm EL, Rosenbaum P. Family-centered theory: origins, development, barriers, and supports to implementation in rehabilitation medicine. Archives of physical medicine and rehabilitation. 2008 Aug 1;89(8):1618-24.

What Is Family-Centered Care?(con…)

Family-centered care is a way of providing services that assures the health and well-being of patients and their families through respectful family/professional partnerships.1

- Hence, the family-centered care theory considers every patient and the family with equal dignity and respect, regardless of race, ethnicity, and cultural background that promotes the recognition of diversity and individual choices of the family and its members.2

It honors the strengths, cultures, traditions, and expertise that families and professionals bring to this relationship.3

1.Patient- and family-centered care and the pediatrician's role. **American Academy of Pediatrics and the Institute for Patient- and Family-Centered Care.** 2, 2012, Pediatrics, Vol. 129, pp. 394-404.

2..Bamm EL, Rosenbaum P. Family-centered theory: origins, development, barriers, and supports to implementation in rehabilitation medicine. Archives of physical medicine and rehabilitation. 2008 Aug 1;89(8):1618-24.

2.Evidence for family-centered care for children with special health care needs: a systematic review. **Kulhthau, Karen, et al.** 2, 2011, Academic Pediatrics, Vol. 11, pp. 136-43.

Family-centered care (FCC)

Broadly defined as promoting a partnership between the parents and healthcare professionals in the care of the child (Smith et al. 2002)

Family-centered care is a partnership approach in health care decision-making between the family and multidisciplinary health care team.

Family-centered care can be defined as a model which provides health services to patients through partnerships that show respect to the family and children.

The practice aims to improve the experiences of patients and family members by reducing stress and maintaining effective communication (Ho, 2020).1

Ho A. Taking family-centered care seriously. The American Journal of Bioethics. 2020 Jun 2;20(6):65-7.

What Is Family-Centered Care?(con…)

The patient's needs in family-centered care are diverse and the theory can be applied to identify all the needs.

The theory notes that health care providers have to interact with patients to ***understand their needs.***

In family-centered care, different family members may need access to varying health care services.

It is the work of the health care providers to work with the family to identify the needs that are central to the family.

This can be done by scheduling meetings with the family members and engaging them in a conversation provision1.

1.Adib-Hajbaghery M, Tahmouresi M. Nurse-patient relationship based on the imogene king's theory of goal attainment. Nursing and Midwifery Studies. 2018;7(3):141-4.

What Is The aim of Family-Centered Care?

Family-centered care is aimed at helping patients identify the right health care services.

- This is made possible through effective communication between health care providers, patient, and family members.
- Heath care providers have to make an effort to understand the patient and help them make better decisions.[1]

A key goal is to promote the health and well-being of individuals and families and to maintain their control.

1.Adib-Hajbaghery M, Tahmouresi M. Nurse-patient relationship based on the imogene king's theory of goal attainment. Nursing and Midwifery Studies. 2018;7(3):141-4.

What are the benefits of Family-Centered Care?

The holistic, collaborative nature of family-centered care can yield a wide range of benefits. These include:

- better health care provider satisfaction,
- more efficient resource allocation,
- improved care delivery, and
- a greater potential for improved patient outcomes.

Family-centered care:

- improves the patient's and family's experience with health care,
- reduces stress,
- improves communication,
- reduces conflict (including lawsuits), and
- improves the health of patients with chronic health conditions (1; 2).

1.Patient- and family-centered care and the pediatrician's role. American Academy of Pediatrics and the Institute for Patient- and Family-Centered Care. 2, 2012, Pediatrics, Vol. 129, pp. 394-404.

2.Evidence for family-centered care for children with special health care needs: a systematic review. Kulhthau, Karen, et al. 2, 2011, Academic Pediatrics, Vol. 11, pp. 136-43.

Patient- and Family-Centered Care(PFCC)

Patient- and family-centered *care is working* ***"with"*** *patients and families, rather than just doing* ***"to"*** *or* ***"for"*** *them.*

Patient- and Family-Centered Care

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is ***grounded in*** mutually beneficial partnerships among health care providers, patients, and families.

It redefines the relationships in health care by placing an emphasis on collaborating with people ***of all ages, at all levels of care, and in all health care settings***.

In patient- and family-centered care, patients and families **define** their "family" and **determine** how they will participate in care and decision-making.

Patient- and Family-Centered Care

This perspective is based on ***the recognition that patients and families*** are ***essential allies for quality and safety***—not only ***in direct care interactions***, but also in ***quality improvement***, ***safety initiatives, education of health professionals, research, facility design, and policy development***.

Patient- and family-centered care leads to ***better health outcomes***, ***improved patient and family experience of care***, ***better clinician and staff satisfaction, and wiser allocation of resources.***

Core Concepts of Patient- and Family-Centered Care

Respect and Dignity.

- Health care practitioners **listen to and honor patient and family perspectives and choices.**
- Patient and family **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.
- Health care providers provide the patient with information on the different options that are available and assists the patient to make a decision.
- Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.

Johnson, B. H. & Abraham, M. R. (2012). *Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities.* Bethesda, MD: Institute for Patient- and Family-Centered Care.

Core Concepts of Patient- and Family-Centered Care

Participation.

- ***Patients and families*** **are encouraged and supported in participating in care and decision-making** at the level they choose.

- Family-centered care was introduced to provide patients with the ability to make decisions on the choice of health care they receive.

Johnson, B. H. & Abraham, M. R. (2012). *Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities.* Bethesda, MD: Institute for Patient- and Family-Centered Care.

Core Concepts of Patient- and Family-Centered Care

Collaboration.

- ***Patients, families, health care practitioners, and health care leaders*** **collaborate in policy and program development, implementation, and evaluation; in facility design; in professional education; and in research; as well as in the delivery of care.**
- Properly delivered family-centered care can ***foster a collaborative relationship*** between the health care professional and the patient.
  - This relationship can lead to a *patient's family members* developing a ***better understanding of the rationale behind certain care delivery strategies.***
  - It can also **allow health care professionals** to ***develop greater respect for a family's cultural values and traditions.***

Johnson, B. H. & Abraham, M. R. (2012). *Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities.* Bethesda, MD: Institute for Patient- and Family-Centered Care.

Principles of Family-Centered Care

- Developing effective family-centered care strategies is a layered process consisting of five essential family-centered care principles.

- Each principle is designed to cultivate trust and collaboration among the health care provider, the patient, and the patient's family.

- This trust is **central** to realizing the benefits of family-centered care.

Principles of Family-Centered Care

1. **Open Communication** with Family Members
   - Communication and information sharing are open and objective.
   - Trust is acknowledged as fundamental.
   - There is a willingness to negotiate.
   - Everyone respects the skills and expertise brought to the relationship.
   - Supports the patient in learning about and participating in his/her care and decision-making.

2. **Recognizing Familial Importance**
   - Acknowledges the family as the constant in a patient's life.
   - Builds on family strengths.
   - Encourages family-to-family and peer support.

Principles of Family-Centered Care

3. Family and Organizational **Collaboration**

- Families and professionals work together in the best interest of the patient and the family.
- Recognizes the importance of community-based services.
- Develops policies, practices, and systems that are family-friendly and family-centered in all settings.

4. Enabling Family Members **to Support Treatment**

- Participants make decisions together.

5. Encouraging Cultural Literacy

- Honors cultural diversity and family traditions.

What Does PFCC Stand For?

Patient- and

Family-

Centered

Care

6/7/2012 2012 Annual Conference, Geneva, New York

PFCC Philosophy

- Treat patients/residents as ***partners*** in care decisions

- Seeing patients/residents as ***unique persons***

"…Guided by ***the needs of the patient***, creating a partnership …across the continuum of care."[1]

"…Ensuring that ***patient values guide all clinical decisions***."[2]

"…A philosophy of health care delivery in which the ***needs of patients and families come before the needs of Care Givers***."[1]

1. Hartford Hospital's Volunteer Handbook.

2. Sood, Gp Capt (Dr) Sanjeev. "Customer-Delight: Imperative for patient-centric care," May 2012, Express Healthcare website. Downloaded from Express Healthcare website on Sunday, May 6, 2012 from http://www.expresshealthcare.in/201205/life01.shtml 6/7/2012 2012 Annual Conference, Geneva, New York

3. "Patient and Family Shadowing Guide: Uncovering Opportunities to Deliver Exceptional Patient and Family Care Experiences," Anthony DiGioia III M.D., Patricia L. Embree, and Eve Shapiro. The Innovation Center, UPMC, 2010, 16. 6/7/2012 2012 Annual Conference, Geneva, New York 10

10 Core Components of PFCC7

1. Human Interaction:

- Patients get nurturing, compassionate, personalized care
- Patients, families and the staff are supported

2. Architectural and Interior Design:

- Facility is welcoming and accessible
- Comfortable, familiar settings
- Architectural barriers that interfere with patients' control and privacy are eliminated

3. The Nutritional and Nurturing Aspects of Food:

Choice and personalized service offered in combination with sound nutritional practices.1

1. "10 Standards of Patient-Centered Care," Gila Regional Medical Center website. Downloaded on Saturday, March 24, 2012 from http://www.grmc.org/Home/About-GRMC/Patient-Centered-Care.aspx 6/7/2012 2012 Annual Conference, Geneva, New York

10 Core Components of PFCC7

4. Information and Education:

- Patients, families and the community given increased access to information
- Patients educated so to participate in treatment decisions

5. Family, Friends and Social Support:

- Involvement of family and others, including volunteers, in the care of patients encouraged

6. Spirituality:

- Chapels, gardens, and similar made available
- Chaplains included as members of the health-care team.1

1. "10 Standards of Patient-Centered Care," Gila Regional Medical Center website. Downloaded on Saturday, March 24, 2012 from http://www.grmc.org/Home/About-GRMC/Patient-Centered-Care.aspx 6/7/2012 2012 Annual Conference, Geneva, New York

10 Core Components of PFCC

7. Human Touch:

- Therapeutic massage, foot rubs and other services to help reduce pain and stress are offered

8. Healing Arts:

- Local artists, musicians, poets and storytellers involved in creating a less-clinical environment

9. Complementary Therapies:

- Aromatherapy, Therapy clowns, Animal-assisted visitation/therapy, other therapies increasingly made available

10.Healthy Communities:

- Expand the boundaries of healthcare by working with schools, churches, civic groups, and other community partners.1

1. "10 Standards of Patient-Centered Care," Gila Regional Medical Center website. Downloaded on Saturday, March 24, 2012 from http://www.grmc.org/Home/About-GRMC/Patient-Centered-Care.aspx 6/7/2012 2012 Annual Conference, Geneva, New York

Benefits of PFCC

- Fewer medical and medication errors
- Better clinical outcomes
- Decreased length of stay and Accelerated recovery time
- Increased reimbursement
- Increased patient/resident satisfaction and loyalty1
- Decreased anxiety
- Decreased emotional distress with better coping during procedures hospitalization post hospital period and recovery2

2. Family-centered care and the pediatrician's role. 3, 2003, Pediatrics, Vol. 112, pp. 691-696. http://pediatrics.aappublications.org/content/112/3/691

Benefits of PFCC (cont.)

Better patient/resident/client to provider/caregiver communication

A united care experience – rather than fragmented, siloed, isolated episodes

Improved employee morale

Decreased staff turnover; decreased nurse vacancy rate

Most importantly, PFCC is :

- The right thing to do
- What patients/residents/clients want

When is the family in need?

While all families have educational needs to prepare for and provide caregiving

However, one quarter of families have extra needs that demand specialist psychosocial care.[1]

The classic times that families struggle include when:

- (I) families with young children have a parent with advanced cancer, including the single parent;
- (II) couple conflict affects the whole family;
- (III) a depressed parent has limited coping;
- (IV) a disabled child will become bereaved; and
- (V) a dysfunctional family with poor communication, unbridled conflict or reduced cohesion has limited coping and support mechanisms for the family.

1. Schuler TA, Zaider TI, Li Y, et al. Typology of perceived family functioning in an American sample of patients with advanced cancer. J Pain Symptom Manage 2014;48:281-8.

2. Kissane DW. The challenge of family-centered care in palliative medicine. Ann Palliat Med. 2016 Oct 1;5(4):319-21.

The challenge of family-centered care in palliative medicine

Palliative care has long aspired to the competent delivery of family-centered care alongside outstanding person-centered care.

Yet there is clear consensus that the unit of care is the patient and family.

Perspectives on family caregiving challenges

In a series of studies of family caregivers for patients with colorectal and lung cancer, Mosher and colleagues identified four consistent challenges experienced by caregivers:

- (I) emotionally coming to terms with disease progression towards end-of-life;
- (II) managing caregiving;
- (III) dealing with uncertainty; and
- (IV) responding to symptom-related suffering (1,2,3).

1. Mosher CE, Adams RN, Helft PR, et al. Family caregiving challenges in advanced colorectal cancer: patient and caregiver perspectives. Support Care Cancer 2016;24:2017-24.
2. Mosher CE, Given BA, Ostroff JS. Barriers to mental health service use among distressed family caregivers of lung cancer patients. Eur J Cancer Care (Engl) 2015;24:50-9.
3. Mosher CE, Bakas T, Champion VL. Physical health, mental health, and life changes among family caregivers of patients with lung cancer. Oncol Nurs Forum,2013;40:53-61.

Psycho-educational interventions to prepare caregivers

- A Swedish collaboration across ten services showed in a randomized controlled trial that a program of three family group educational sessions by physician, nurse and social worker/chaplain significantly increased family caregivers preparedness for and competence in caregiving.1
- However, no effects were found on emotional issues including anxiety and depression.
- A structured review of family meetings at the end of life synthesized findings from 24 studies and noted that family satisfaction increased when the clinician allowed time for family speaking, provided assurance to alleviate patient suffering and not abandon the patient, while also supporting family decisions.2

1. Holm M, Årestedt K, Carlander I, et al. Short-term and long-term effects of a psycho-educational group intervention for family caregivers in palliative home care - results from a randomized control trial. Psychooncology 2016;25:795-802.

2. Sullivan SS, da Rosa Silva CF, Ann Meeker MA. Family Meetings at End of Life: A Systematic Review. J Hosp Palliat Nurs 2015;17:196-205.

Psycho-educational interventions to prepare caregivers

- The biomedical model at family meetings educates about prognosis, medical and pharmacological care needs and decisions about end-of-life care.

- When agenda setting was not purposeful at the start of the meeting, families reported feeling rushed and emotionally unprepared for what occurred.

- As the family meeting becomes routine for all inpatient palliative care admissions, adoption of a structured model has been seen as crucial to adequately address family needs.2

1. Holm M, Årestedt K, Carlander I, et al. Short-term and long-term effects of a psycho-educational group intervention for family caregivers in palliative home care - results from a randomized control trial. Psychooncology 2016;25:795-802.

2. Sullivan SS, da Rosa Silva CF, Ann Meeker MA. Family Meetings at End of Life: A Systematic Review. J Hosp Palliat Nurs 2015;17:196-205.

Identification of and intervention with difficult families

Most challenging to support are those families in conflict who block easy communication and where family ruptures and separations lead to unavailability for care provision and support.

A routine screening model of family functioning was developed in Australia and replicated in the USA to use the 12-item Family Relationships Index (FRI) with good sensitivity to detect families with low communication, low involvement and high conflict[1].

These families are at risk and in need for psychosocial support.

Clinicians in individual consultations or family meetings can also ask three simple questions about family relational life to discern the presence of any dysfunctionality:

- (I) communication— how openly do you communicate as a family?
- (II) cohesion—how strong is family teamwork and mutual support?
- (III) conflict—how well do you resolve arguments and differences of opinion?

1.Schuler TA, Zaider TI, Li Y, et al. Typology of perceived family functioning in an American sample of patients with advanced cancer. J Pain Symptom Manage 2014;48:281-8.

Special family needs

Clinicians do well to recognize the particular predicaments that challenge even resilient families, for instance:

- the expected death of a parent with younger children[1],
- the dying parent of a disabled child[2], and
- when a conflictual marriage strains relationships for the rest of the family3.

1. Moore CW, Rauch PK. Addressing the Needs of Children When a Parent Has Cancer. In: Holland JC, Breitbart WS, Jacobsen PB, et al. editors. Psycho- Oncology. Third Edition. New York: Oxford University Press, 2015:579-84.
2. Muriel AC. Care of Families with Children Anticipating the Death of a Parent. In: Kissane DW, Parnes F. editors. Bereavement Care for Families. New York: Routledge, 2014:220-31.
3. Northouse LL, McCorkle R. Spouse Caregivers of Cancer Patients. In: Holland JC, Breitbart WS, Jacobsen PB, et al. editors. Psycho-Oncology. Third Edition. New York: Oxford University Press, 2015:567-73.

Structured models of family-centered care

The future of competently-delivered family-centered care depends on services adopting a structured approach to family care.

A two-tiered approach is needed:

- At the first level, routine family psycho-education is needed for all, and should be accompanied by routine family screening for the quality of relational life with the FRI.
- A routine family meeting is a desirable standard of care for all inpatient palliative care delivery.
- At the second level, those 20% of families whose FRI scores suggest greater risk should be invited for an outpatient assessment family meeting where their concerns and needs are identified in an effort to provide them with the rationale to continue family-focused therapy.
- Here the ongoing goal of enhancing their emotional support for one another would be agreed upon during both palliative care and extended into bereavement.

THANKS

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