



A2.2 – Educative resources for teachers

FAMILY-CENTERED CAREGIVING

Module: 6 – SPECIFIC TRAINING

Sub-Module: 6.4. Family-Centered Caregiving



Introduction

Module	SELF-CARE
Sub-module	FAMILY CENTERED CAREGIVING
Lesson nr.	#1
Duration (minutes)	90
Date	

Lesson Outcomes

1. Family structure
2. Cultural diversity
3. The most common long-term states
4. Family centered caregiving

My family

There are many family structures

1. Nuclear (two parents and children) - different gender parents or same gender parents
2. Single parent family
3. Extended family (at least 3 generations)
4. Joint family (after a divorce or widowing person finds another person with or without children)
5. Childless family (only a couple)
6. Stepfamily or adoptive family
7. Foster family or temporary family
8. Grandparent family

Important others

Some people do not have good or any relationship with family members.

We have to respect that. They probably have important others for support.

1. Relatives (aunt, uncle, cousin, ect)
2. Neighbourghs
3. Friends
4. Acquaintance
5. Others

Cultural diversity and cultural differences

Cultural diversity and differences starts in a FAMILY. Family has its own language, tradition, religion, beliefs, values, history, food, depending much on location /state/ place of living, social and economic status, age, ect.



TASK 1 – my family/your family

1. Create small groups of 3-5 participants
2. Write down 5-10 things that defines your family and makes it different from others
3. Compare your families and discuss cultural differences
4. Facilitate group discussion

Cultural differences

When entering to another home or family we have to respect their culture.

When taking care or being a caregiver of your-own family member than cultural aspect is less visible and/or important, since you might share common values, beliefs, religion.

If not so, the most important things are RESPECT and UNDERSTANDING.

- Ask questions if you have doubts.
- Do not judge

Long term conditions (LTC)

The most common long term conditions where care is needed are

1. Cancer
2. Neurological diseases
3. Stroke
4. Coronary heart disease
5. Cognitive impairment
6. Chronic kidney disease
7. Chronic obstructive pulmonary disease
8. Diabetes ect.

When diagnosed...

Many people are going through **stages of grief**:

1. Denial
2. Anger
3. Bargaining
4. Depression
5. Acceptance

Family members/important others are also strongly involved. They all need **SUPPORT**.

Disease/condition is here – how can we go on

Acceptance and coping are necessary to achieve a positive living. Coping involves behavioral and cognitive strategies fo adjust.

Patient and family/impotrant others further try to deal with:

1. Self-management (how and what can carer/patient still do, self-managemet of caregivers life)
2. Intergation
3. Adjustment

Mechanisms of coping and adjusting

1. Awareness of the situation of change created by a LTC
2. Personal networks
3. Information and education about the LTC
4. Personal conditions (previous experiences, socioeconomic status, ect)
5. Attitude to life
6. Communication

TASK 2 – self-reflection

Take time to answer to this questions.

1. Have you ever experienced grief?
2. How did you feel? Try to describe emotional and physical problems that occurred.
3. Who gave you the support?
4. How did you cope with and adjust to the situation?

If comfortable facilitate reporting and group discussion.

Cancer

The most spreaded cancer are: breast, lung, prostate, colon, melanoma, bladder, ect.

Most common ways of treatment are:

- Operation/surgery
- Chemoterapy
- Radiotherapy

Treatment strategies can be combined and depend on the cancer type.

Chemo is the most aggresive and has the most negative sideeffects (vomiting, nausea, diharrea, hair loss, hemoraghie, chronic pain, bladder and kidney problems, disphagia, ect)

Patient with cancer need

1. Love and support – be there (consider support group)
2. Peace and rest for recovery
3. Possible assistance with basic needs (feeding, eliminating, hygiene, clothing, sleeping, moving and transporting)
4. Supervision and support with food and liquid intake (when and what they like)
5. Supervision and support with medications
6. Be patient, time is not important for some things,

Neurological conditions

The most common long-term neurological conditions where people need assistance and care are: stroke, multiple sclerosis, Parkinson disease, tumours, dementia, epilepsy, ect. Each condition is unique, so also patients experiences and symptoms are unique.

Symptoms that can often occurs:

1. Vomiting, nausea
2. Severe headache
3. Confusion
4. Speech problems
5. Orientation problems
6. Vision loss, double vision
7. Weakness in legs, arms, coordination and balance problems
8. Tingling
9. Incontinence or retention

Patient with neurological condition need

1. Love and support – be there (consider support group)
2. Assistance with basic needs (feeding, eliminationg, hygiene, clothing, movment)
3. Verbal communication can be aggrevated or absent
4. Decline of cognitive functions (speech, understanding, recognition, learning, thinking)
5. Emotinal distress
6. Tactile function can be affected

Diabetes

Diabetes is a serious disease. Careful care can reduce life-threatening complications:

1. hypoglycemia (low blood sugar) or hyperglycemia (high blood sugar)
2. Dehydration or diabetic ketoacidosis
3. Nephropathy (kidney damage)
4. Neuropathy (nerve damage)
5. Retinopathy (eye damage)
6. Foot problems (diabetic foot ulcer)
7. Hearing impairment
8. Heart attack /stroke, ect

Patient with diabetes need

1. Love and support (consider support group)
2. Help with controlling blood sugar and managing diabetes
3. Quit smoking
4. Regular control of blood pressure and cholesterol
5. Regular check up at doctor (GP, specialist)
6. Regular physical and eye exams
7. Care for dental/oral health
8. Care of feet/pedicure (neuropathy)
9. Consider a daily aspirin (risk of cardiovascular diseases)
10. Limit alcohol assumption
11. Take stress seriously

Coronary heart disease (CHD)

The main symptoms are:

1. Chest pain
2. Shortness of breath
3. Pain throughout the body
4. Feeling faint
5. Nausea

The main causes of coronary heart disease:

1. Atherosclerosis (lifestyle factors – smoking, alcoholism)
2. High cholesterol
3. High blood pressure
4. diabetes

Patient with heart disease need

1. Love and support
2. Change the lifestyle (healthy eating, balanced diet, giving up smoking, drinking alcohol, physical activity)
3. Regular check up at doctor
4. Regular control of blood pressure, blood sugar and cholesterol
5. After heart attack, anygioplasty, or heart surgery, it's possible to recover and get back to normal life

Chronic pain

Persistent pain lasting 12 weeks or more despite medication or treatment.

1. It can occur after surgery, fracture, injury...
2. Can affect people with diabetes, arthritis, fibromyalgia, irritable bowel back pain...
3. It affects many people, is a public-health problem
4. The most common types:
 - Headache
 - Postsurgical pain
 - Post-trauma pain
 - Lower back pain
 - Arthritis pain
 - neurogenic pain
 - psychogenic pain
 - cancer pain

Patient with chronic pain need

1. Love and support (consider support group)
2. Regular medications (drugs) for chronic pain
3. Supportive procedures/therapy (electrical stimulation, nerve block, acupuncture, surgery...)
4. Lifestyle remedies (physical therapy, tai chi., yoga, art and music therapy, pet therapy, psychoterapy, massage, meditation)
5. Try to conutinue daily routine and activities
6. Take care of their body (eating well, enough sleep, exercise regularly, reduce stess)

Child long term conditions

1. Cancer
2. Children Mental disorders (CMD) (anxiety, depression, eating disorders, obsessive-compulsory disorder, post-traumatic stress disorder, Tourette syndrome, ect)
3. Neurological disorders (seizures, encephalopathy, congenital neurological defects, ect)
4. Neurodevelopmental disorders (intellectual disability, ADHD – attention-deficit/hypeactivity disorder, autism spectrum disorder)
5. Congenital heart defect (CHD)
6. Diabetes ...

Child and parents with LTC need

1. Love and support – be there (consider support group)
2. Parents need relevant information from doctors, health care workers about the disease/condition, the severity, treatment options, length of treatment, possible recovery, options for institutions, financing, ect.
3. Childs' needs depends on age and condition
4. No pain, safety and comfort – the most important things for a child

TASK 3 – working with children

1. Create groups of 8-10 members
2. Each group should now divide into 2 smaller groups (A and B)
3. Group A discuss and write down the advantages of working with children with LTC (3-5 minutes)
4. Group B discuss and write down disadvantages of working with children with LTC (3-5 minutes)
5. Present and discuss in primary group (5 minutes)
6. Joint conclusions from all groups can be made

Core concepts of patient- and family-centered care (PFCC)

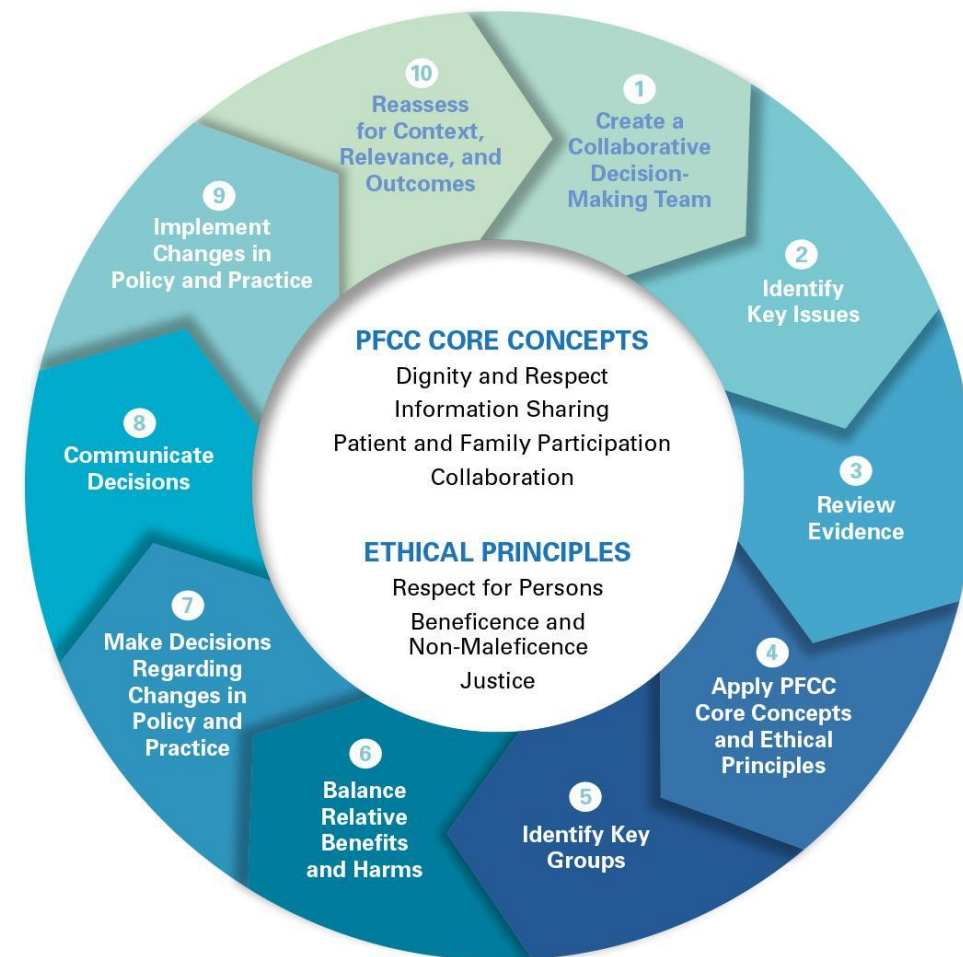
1. **Dignity and Respect.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
2. **Information Sharing.** Health care practitioners 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.
3. **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
4. **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.

Patient- and Family-Centered Care (PFCC)

Process of PFCC

1. Create a team
2. Identify key issue
3. Review evidence
4. Apply PFCC core concepts and ethical principles
5. Identify key groups
6. Balance benefits and harms
7. Make decisions
8. Communicate decisions
9. Implement changes
10. Reassess

An Iterative Process for Decision-Making Within a Patient- and Family-Centered Ethical Framework



Family-centered care for children

1. Acknowledges the family as the constant in a child's life.
2. Builds on family strengths.
3. Supports the child in learning about and participating in his/her care and decision-making.
4. Honors cultural diversity and family traditions.
5. Recognizes the importance of community-based services.
6. Promotes an individual and developmental approach.
7. Encourages family-to-family and peer support.
8. Supports youth as they transition to adulthood.
9. Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
10. Celebrates successes.

Partnership

1. Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.
2. Everyone respects the skills and expertise brought to the relationship.
3. Trust is acknowledged as fundamental.
4. Communication and information sharing are open and objective.
5. Participants make decisions together.
6. There is a willingness to negotiate.

Pediatric family-centered care interventions and practices 1

1. Respecting each child and his or her family
2. Honoring racial ethnic cultural and socioeconomic diversity and its effect on the family's experience and perception of care
3. Recognizing and building on the strengths of each child and family even in difficult and challenging situations
4. Supporting and facilitating choice for the child and family about approaches to care and support
5. Ensuring flexibility in organizational policies procedures and provider practices so services can be tailored to the needs beliefs and cultural values of each child and family

Pediatric family-centered care interventions and practices 2

6. Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming
7. Providing and/or ensuring formal and informal support (e.g. family-to-family support) for the child and parent(s) and/or guardian(s) during pregnancy childbirth infancy childhood adolescence and young adulthood
8. Collaborating with families at all levels of health care in the care of the individual child and in professional education policy making and program development
9. Empowering each child and family to discover their own strengths build confidence and make choices and decisions about their health

Benefits to families

1. Decreased anxiety
2. Accelerated recovery time
3. Reduced crying and restlessness
4. Decreased emotional distress with better coping during procedures hospitalization posthospital period and recovery
5. Increased parent confidence and problem-solving capacity
6. Improved mental health status of mothers of children with chronic illness

Benefits to hospital/clinics

1. Improved hospital patient and family satisfaction scores
2. Improvement on standardized measure of medical home implementation
3. Improved staff satisfaction

Benefits to pediatricians

1. A stronger alliance with the family in promoting each child's health and development
2. Improved clinical decision making on the basis of better information and collaborative processes
3. Improved follow-through when the plan of care is developed collaboratively with families
4. Greater understanding of the family's strengths and caregiving capacities
5. More efficient and effective use of professional time and health care resources (e.g. more care managed at home decrease in unnecessary hospitalizations and emergency department visits more effective use of preventive care)
6. Improved communication among members of the health care team
7. A more competitive position in the health care marketplace
8. An enhanced learning environment for future pediatricians and other professionals in training
9. A practice environment that enhances professional satisfaction

PFCC during the pandemic

Absence of family members/important ones in hospital due to epidemic regulations increased anxiety and stress among patients and family.

- Isolation leads to loneliness, emotional problems and depression
- Interrupted bonding
- Decreased care and learning opportunities
- Communication breakdown and the lack of information
- Quick changes of regulations, rules increase stress

TASK 4 – short video

Institute for patient- and family-centered care[®] has on a web page short video.

<https://www.ipfcc.org/about/pfcc.html>

1. After seeing this video, THINK and COMPARE with family-centered care concept to your experiences in health care system.
2. Reflect with other, group discussion



GIVINGCARE
Empowering Caregivers

Thank you!

Teachers's name

Teachers e-mail

Date of the session

