Families in Palliative Care

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UCT

Family and Palliative Care

- Palliative care is an approach that improves the quality of life of ***patients and their families*** facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
  - offers a support system to help the family cope during the patients illness and in their own bereavement;
  - uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;

Family System Theory

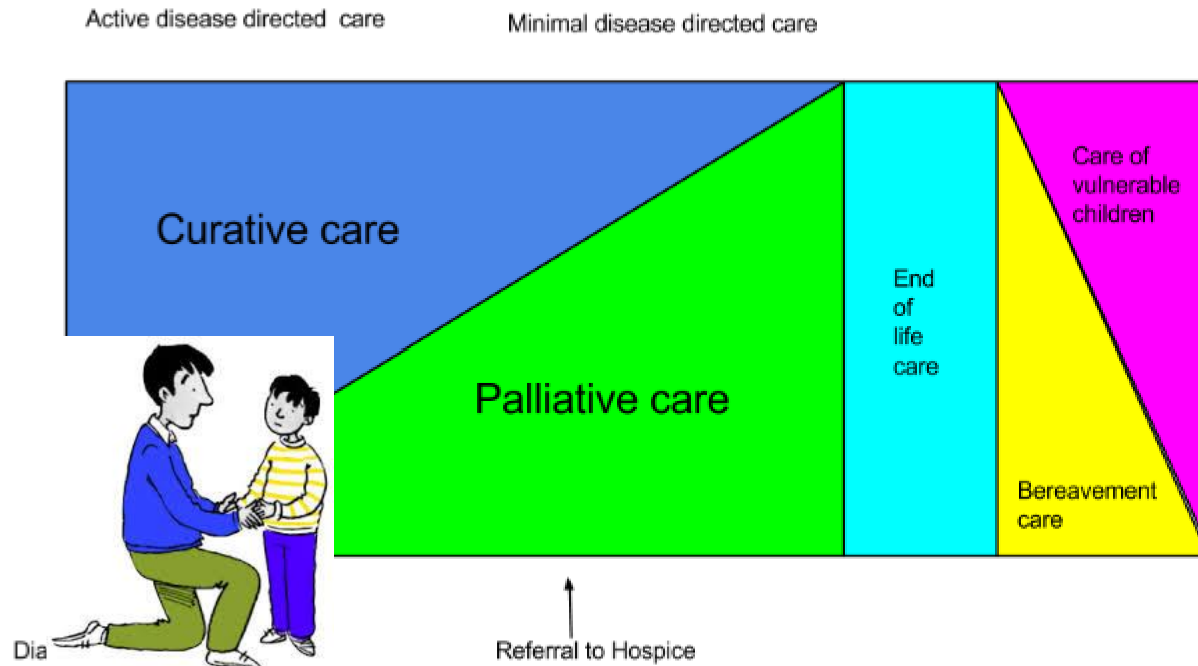
The individual is part of a larger emotional system of the family, with the family seen as the whole.

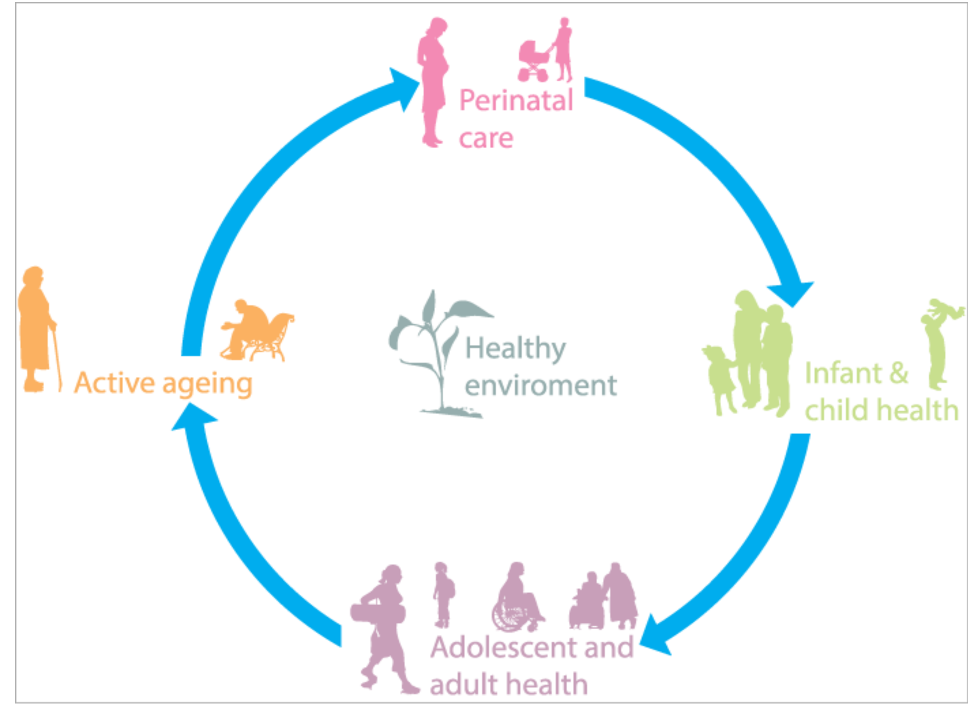
- The whole is greater than the sum of the parts.
- Whatever affects the system affects each part.
- A change in any part of a system affects every part of the system and the system as a whole.

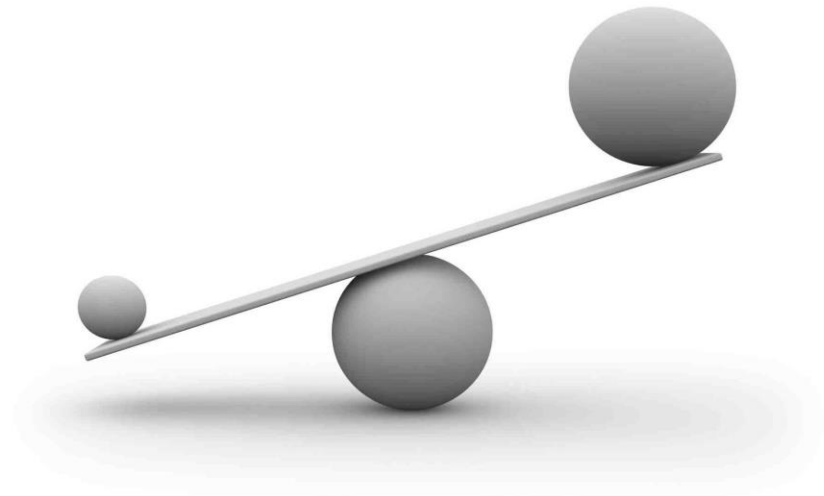
My own domino effect:

Families and the continuum of care:

- "Unit of care"
- Adaption and role change




Perinatal
care
Healthy
enviroment
Infant &
child health
Adolescent and
adult health
Active ageing



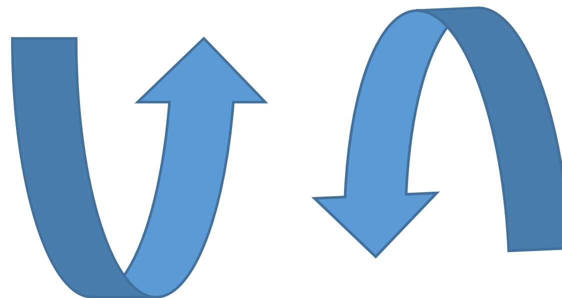
Family interaction models of Minuchen

Enmeshed

- Identities of individual interconnected
- Restrict contact with outside world
- Uses covert rules
- Find it difficult to accept help from outside
- Communication is difficult

Disengaged

- Very little mutual dependence
- Encourages support from outside world
- Little sharing of function
- More flexible
- Communication must be clear.



Low	C O H E S I O N	High

high
A
D
A
P
T
A
B
I
L
I
T
Y
low
low

levels of flexibility

CHAOTICALLY DISENGAGED

CHAOTICALLY SEPARATED

CHAOTICALLY CONNECTED

CHAOTICALLY ENMESHED

FLEXIBILY DISENGAGED

FLEXIBLY SEPERATED

FLEXIBLY CONNECTED

FLEXIBLY ENMESHED

STRUCTURALLY DISENGAGED

STRUCTURALLY SEPERATED

STRUCTURALLY CONNECTED

STRUCTURALLY ENMESHED

RIGIDLY SEPERATED

RIGIDLY CONNECTED

RIGIDLY DISENGAGED

RIGIDLY ENMESHED

CHAOTIC
Lack of leadership
Dramatic role shifts
Too much change
Erratic discipline

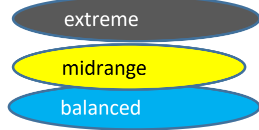
FLEXIBLE
Shared leadership
Role sharing
Democratic discipline
Change when necessary

STRUCTURED
Leadership sometimes shared
Roles stable
Somewhat democratic discipline
Change when demanded

RIGID
Authoritarian leadership
Roles seldom change
Strict discipline
Too little change

Levels of cohesion

DISENGAGED I	**SEPERATED I/we**	**CONNECTED I/WE**	**ENMESHED WE**
Little closeness, lack of loyalty **High independence**	Low/moderate, little loyalty **Interdependent –** more independence than dependence	Moderate/high, some loyalty **Interdependent –** more dependence Than independence	Very high closeness, high loyalty **High dependency**



Who do we interact with?

Spokesperson

Decision maker

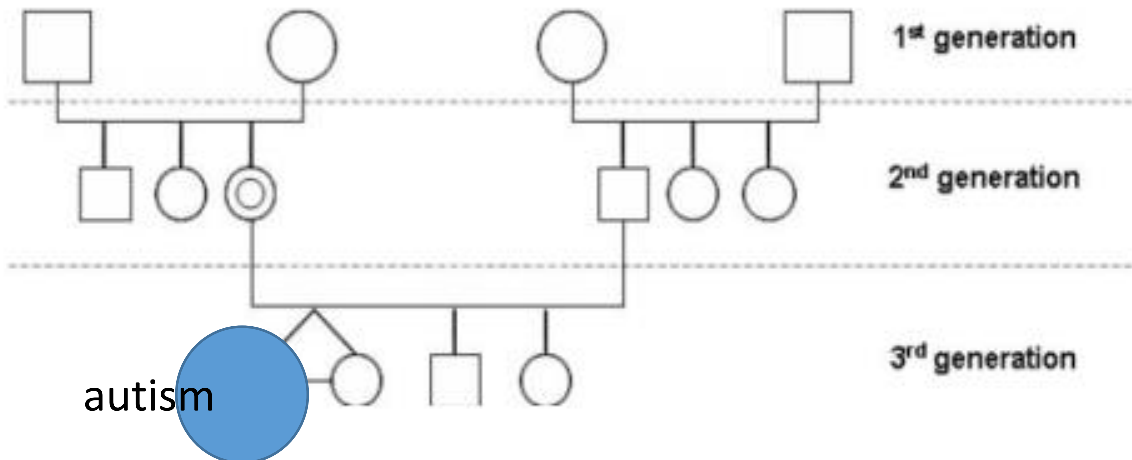
Carer

Vulnerable

FAMILY MAPPING

- Genograms
- Understanding the roles, rules and hierarchies
- Assessing structure
- Transactional patterns
- Flexibility
- Ability to restructure
- Resonance – acknowledging family behaviours, life context , supports and stressors, family life development stage
- What maintains the problem within these interactions.

Genograms



Example of a Three-Generation Genogram

Key goals of a family meeting:

- Open communication and collaboration.
- Identifying issues of concerns for a family.
- Identifying past patterns of relating to illness.
- Problem solving around key aspects of care.
- Encouragement and acceptance of community support.
- Affirmation of care and support.
- Acknowledgement of their inherent suffering.
- Encouragement of their own coping skills

Oxford Textbook of Palliative Medicine box 17.6.2

Road map to a family meeting:

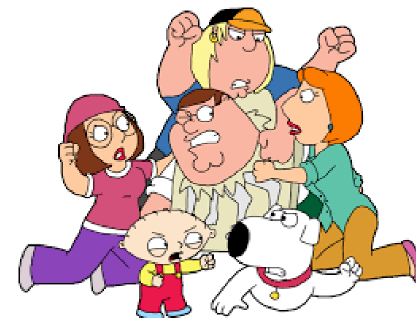
- Plan ahead: when, where and who?
- Setting.
- Welcome and orientate family to the goals of the meeting.
  - Normalise the meeting
- Check each family members understanding of the illness and prognoses.
- Check in on their current goals of care.
- Identify their concerns regarding symptoms and care concerns.
- Discuss future care in relation to the amount of information they want.
- Identify how families are coping and feeling.
- Identify family strengths and their support of each other and the patient.
- Close by summarising agreed goals and future care plans.

Oxford Textbook of Palliative Medicine box 17.6.3

Specific facilitation techniques:

- Circular questions.
  - Each family talks about their concerns and reflect on their own and other members emotions.
- Reflective questions.
  - Ask family members to hypothesise on outcomes or care issues e.g. *what benefits might there be for caring for dad at home?*
- Strategic questions.
  - Incorporating solutions in your questions e.g. *what symptoms will make you bring dad back to hospital?*
- Summary of family discussion with family agreement.
  - Emotions, goals and solutions are summarised and fed back to the family to comment on.

Working with complex families:



- Agree beforehand who is leading the meeting and plan ahead what other team members might be needed.
- “Sing the same song”
- Have an open door.
- Make sure you are talking to the right people (all the different factions of a family and do not choose sides)
- Create more rigid structure in the meeting beforehand:
  - Time
  - Set firm limits on how interaction will take place
  - Be clear that abuse will not be tolerated
- Encourage family members to talk to you regarding concerns and not shouting abuse to other family members.
- Ensure everybody gets a turn to talk
- Do not try and solve all the problems.
- Debrief with your team afterwards

Proot IM, et al Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. Scandinavian Journal of Caring Sciences. 2003;17(2):113-21.

Individual care: Carer Support Needs Assessment Tool (CSNAT)

- Support domains to enable carer to care

- More direct support domains for carers themselves

Ewing G. The Carer Support Needs Assessment Tool (CSNAT) for Use in Palliative and End-of-life Care at Home: A Validation Stud. Journal of Pain & Symptom Management. 2012;46(3):395-405.

Support domains to enable carer to care

Do you need more support with .

- understanding your relative's illness?
- managing your relative's symptoms, including giving medicines?
- providing personal care for your relative (e.g. Dressing, washing, and toileting)?
- knowing who to contact if you are concerned about your relative (for a range of needs, including at night)?
- equipment to help care for your relative?
- talking with your relative about his or her illness?
- knowing what to expect in the future when caring for your relative?

Ewing G. The Carer Support Needs Assessment Tool (CSNAT) for Use in Palliative and End-of-life Care at Home: A Validation Stud. Journal of Pain & Symptom Management. 2012;46(3):395-405

More direct support domains for carers themselves

Do you need more support with .

- having time for yourself in the day?
- your financial, legal, or work issues?
- dealing with your feelings and worries?
- looking after your own health (physical problems)?
- your beliefs or spiritual concerns?
- practical help in the home?
- getting a break from caring overnight
- Own bereavement

Ewing G. The Carer Support Needs Assessment Tool (CSNAT) for Use in Palliative and End-of-life Care at Home: A Validation Stud. Journal of Pain & Symptom Management. 2012;46(3):395-405

The reality of the African setting:

- Most care has to be conducted with families with very limited resources.
- Many families live far apart from each other.
- Families are a vital part of long term care.
- Families are inherently dissatisfied with care in the public sector.
- Severe illness heighten this dissatisfaction leading to complaints.
- HCW have limited time to interact and support families.
- Doctors need the skills and attitudes to manage the family within a family system.
- You might have only one chance to identify the vulnerable members of a family.

Vulnerable populations in families

- Children
  - Ensuring future care
  - Ensuring bereavement support
  - Identifying their role in care

- Mental illness
  - ongoing care outside
  - Education around triggers
  - Ability to care for the patient
- Elderly carers
  - Own health
  - Social isolation
- Refugees
- Prisoners

Families are vital collaborators in healthcare !

Thank you