DIMENSIONS OF PATIENT CARE
WHAT THE DOCTOR DOES NOT SEE

DF Wittenberg

This is a complicated case
We will need to admit and investigate
I have no beds today. The patient could return in a few days' time

What does this mean? Will my child recover? Is this bad? Will he die?
Is it my fault? What will the family say?
I have to get back to the other children!
How long will I be away from work?
What will this cost?

Patient care has many more dimensions than the purely medical aspect of making a diagnosis and managing the disease

Outline

- Changed physician role in health care
- Patient and parent responses to serious illness
- The doctor-patient dyad in Paediatrics
- Patient and doctor needs beyond medical issues
- The changing doctor-patient contract in chronic disease

HISTORICAL EVOLUTION OF PATIENT CARE

Previously: Spiritual, emotional, social and physical care in a continuum, with the healing role usually vested in someone with religious authority

- **Spiritual**
  - Assignment of guilt
  - Invoke divine intervention and appeasement
  - To allay fear and instil hope and confidence
- **Rituals**
  - To invoke authority and "set the scene"
  - For social solidarity and support
- **Physical**
  - Medications and procedures

HISTORICAL EVOLUTION OF THE DOCTOR'S ROLE IN PATIENT CARE

Modern trends: Specialisation, segmentation and fragmentation, role restriction, less personal involvement. Patient decisions as team effort, therefore more anonymous for the patient

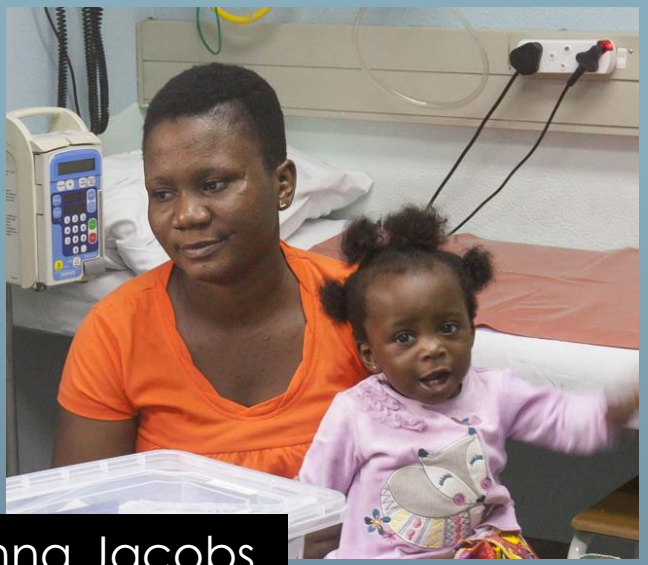
For the doctor, this often means:

- Focus on the organ system and its disease
- Other issues risk being ignored or referred to another service provider
- Loss of holistic care

Unmet patient needs on several levels

Parent's emotional responses to a child's severe illness

Fear, anxiety, anger, helplessness, depression All the stages of grief
Shock, denial, bargaining, acceptance
Why? Whose fault is this?
Something or somebody to blame?
Punishment for some prior issue?
Why me ?
Congenital syndrome or disorder



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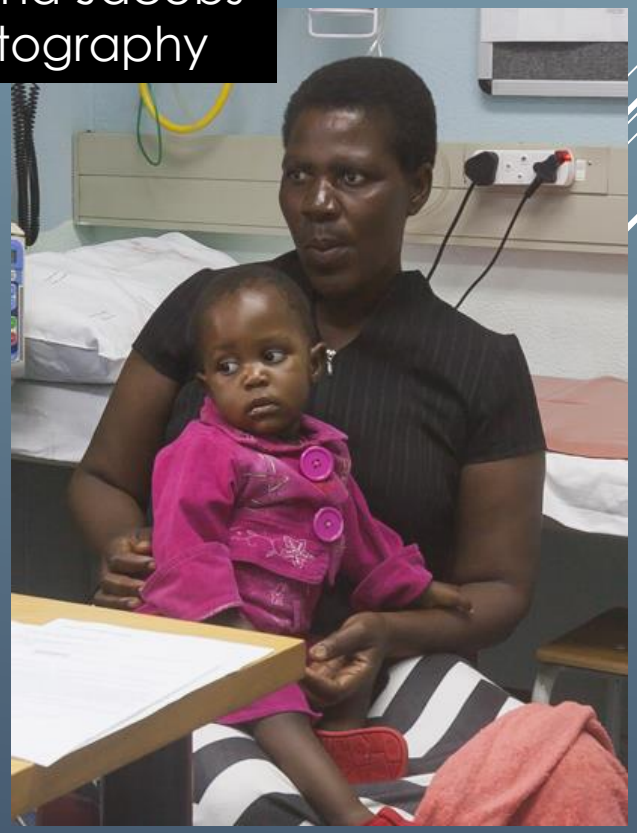


We should assume that the parent is experiencing one or more such emotional responses, but there are wide inter-individual and intercultural differences in being able to express them

DOCTOR- PATIENT DYAD IN PAEDIATRICS

- Interaction between

  Doctor – Mother,

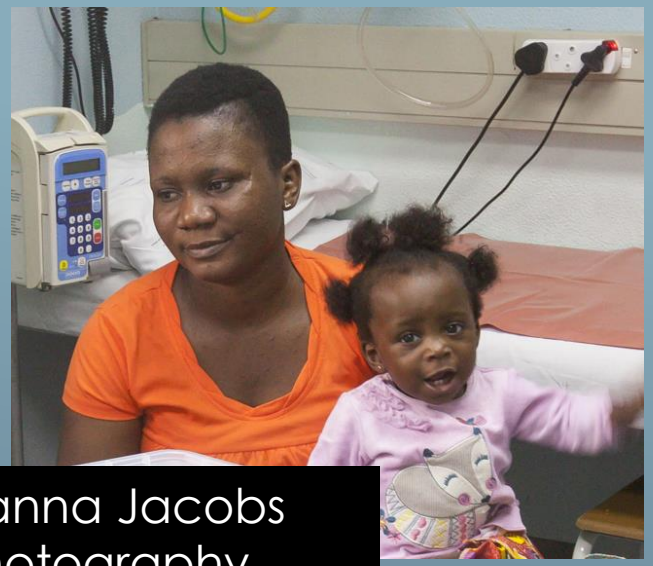
  Mother - Child

  Doctor - Patient

- Multiple determinants of quality of interaction

What affects mother's interaction with the doctor?

- Social circumstances
  - Social or class gap
  - Power differential
  - Racial stereotypes and assumptions
- Educational attainment and insight
  - Use of information
- Language barriers
  - Loss of nuances and deeper meaning
  - Incorrect use of words and concepts



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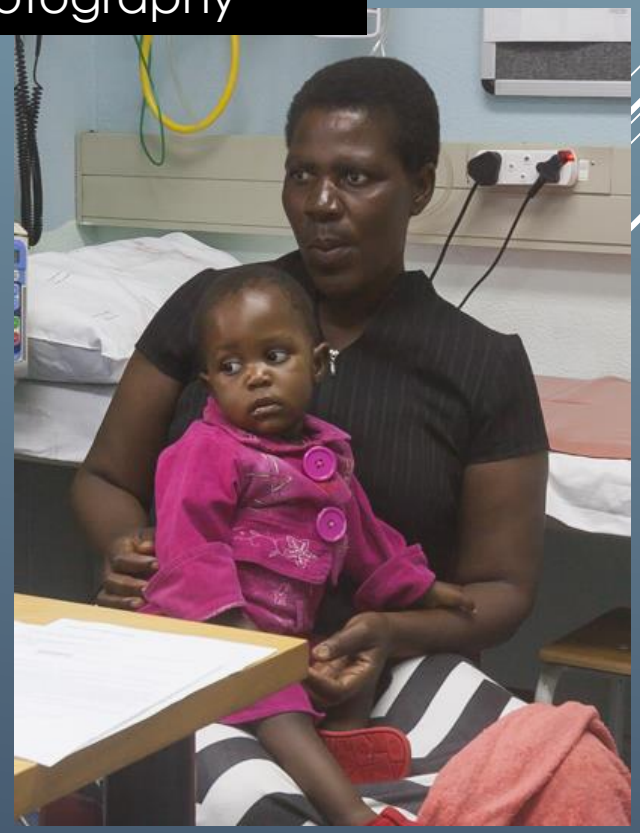
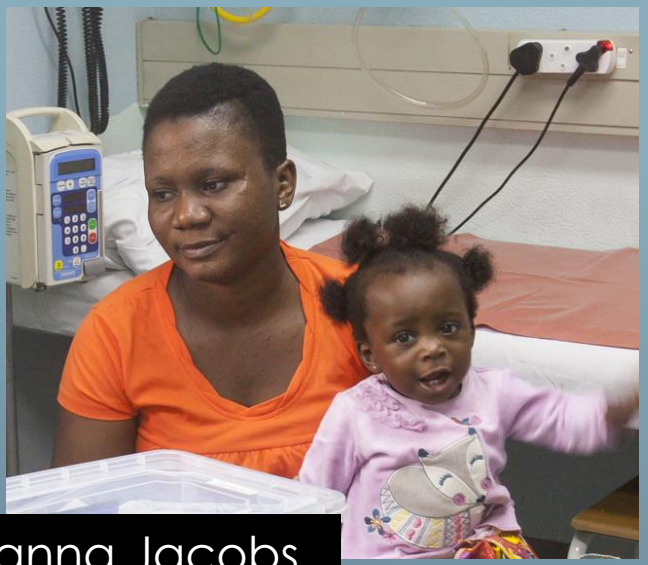


What affects mother's interaction with the doctor?

- Social circumstances
- Educational attainment
- Language barriers
- Prior "knowledge" or assumptions
  - Google and "symptom match"
  - Preconceived ideas or fears
    - *This is…*
    - *My child has….*

Doctor's opinion may be rejected



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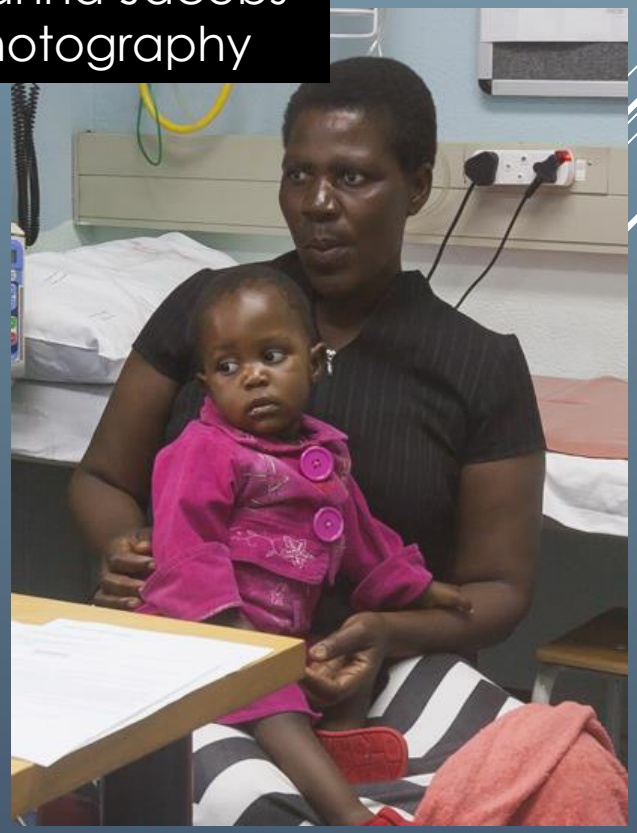
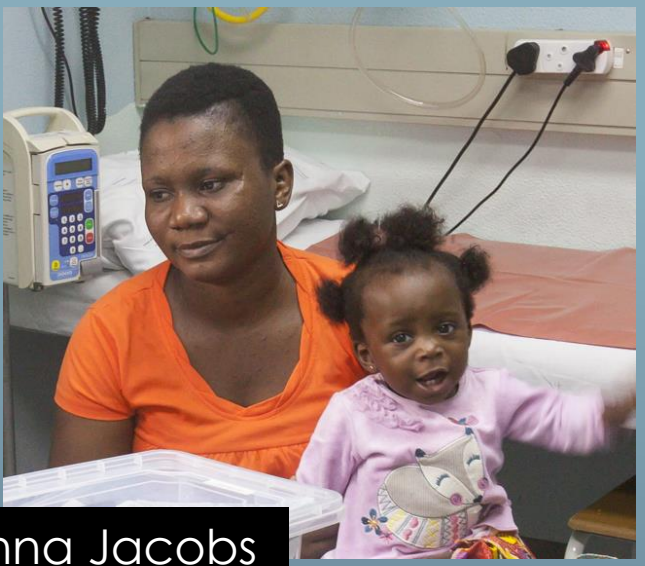


What affects mother's interaction with the doctor?

- Social circumstances
- Educational attainment
- Language barriers
- Prior "knowledge" or assumptions
- Religious Outlook
  - God's punishment ?
- Life experiences
  - Previous deaths with similar problems
  - Family dynamics: partner, grandparents
  - *Accusations*
  - Emotional state: depression, anxiety



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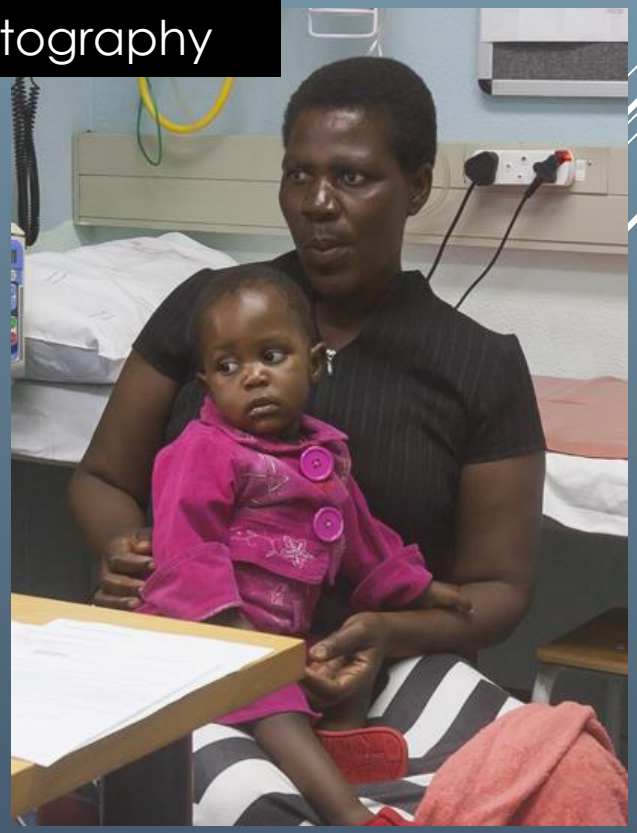


WHAT AFFECTS THE DOCTOR IN HIS/HER INTERACTION WITH THE PATIENT AND MOTHER?

- Social and class differences

  Difficult to understand patient's different realities
- Own life or professional experiences

  May cloud one's professional judgement

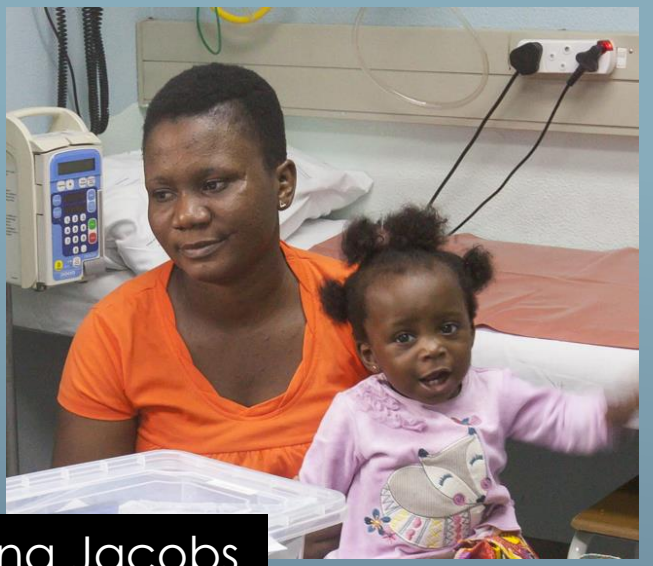
  Uncertainty regarding diagnosis and correct choices
- Religious and attitudinal outlook on life

  Especially if different to that of the patient's family
- Personal sympathy or antipathy for the client

  It may be difficult to achieve true empathy

What affects mother's interaction with the doctor?

- Social circumstances
- Educational attainment
- Language barriers
- Prior "knowledge" or assumptions
- Religious Outlook
- Life experiences
- Doctor's responses to mother



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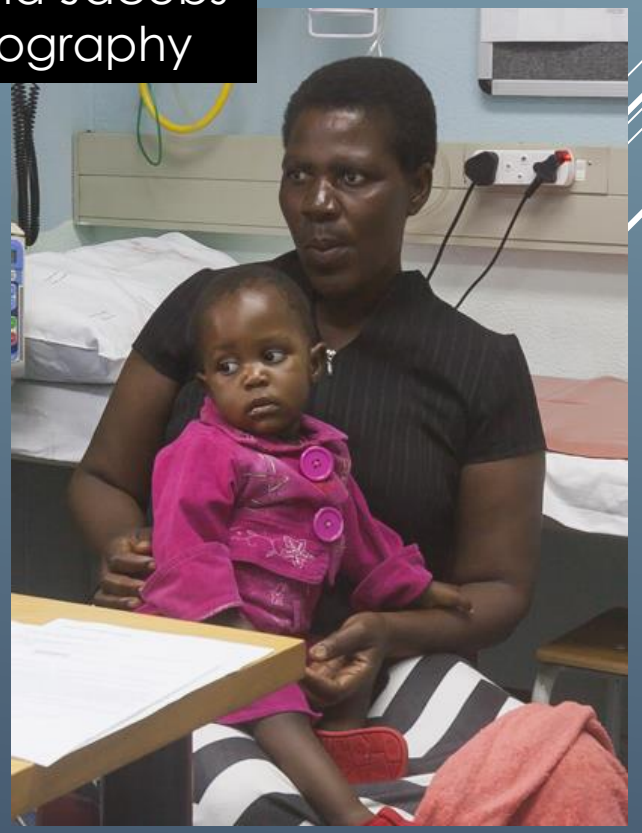

Mother may be quite unable to even hear, to comprehend or have an empowered response

This is particularly important in situations requiring informed responses to management options

THE PATIENT IS THE CHILD

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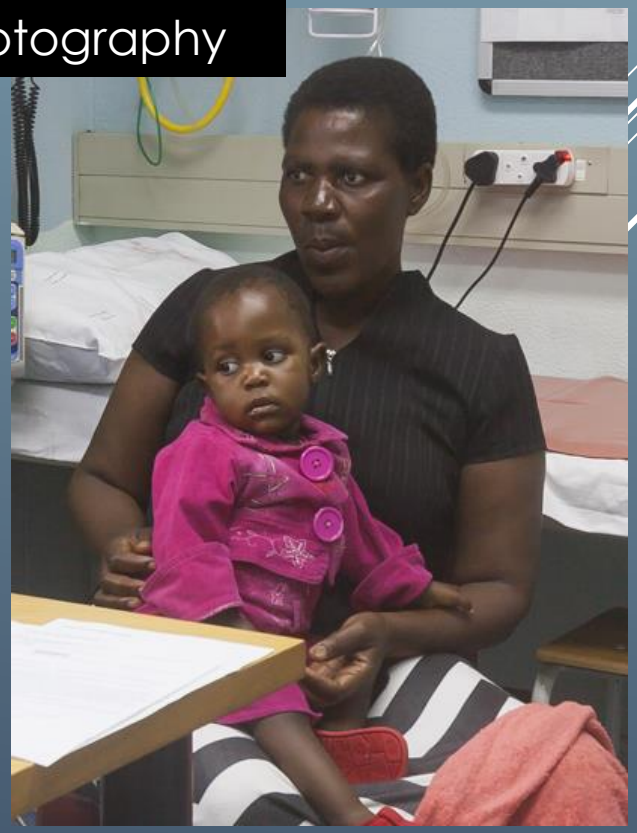
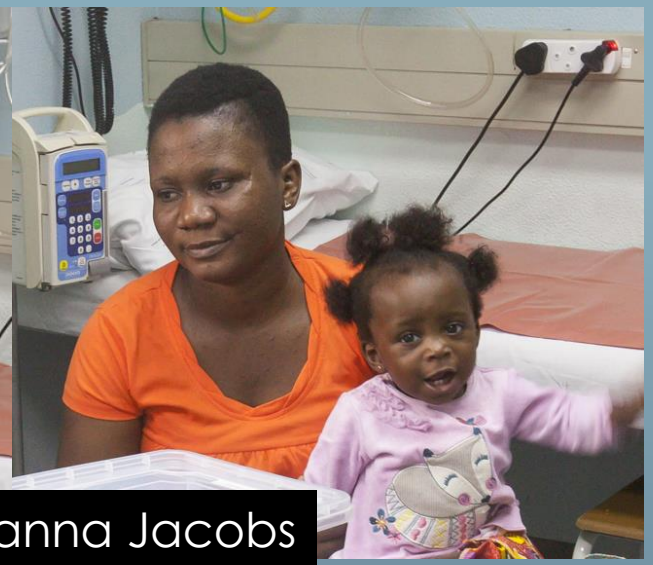


<u>What affects mother's interaction with her child?</u>

- Pregnancy experiences –
  - wanted/unwanted
  - only child or one of several
- Extent and quality of care
  - cared for by grandmother
  - mother unable to provide
- Feelings of guilt, burden, anxiety

What affects child's reaction to mother?

- Illness, weakness
- Child's position in the family
- Intra-family security and confidence
- Developmental stage



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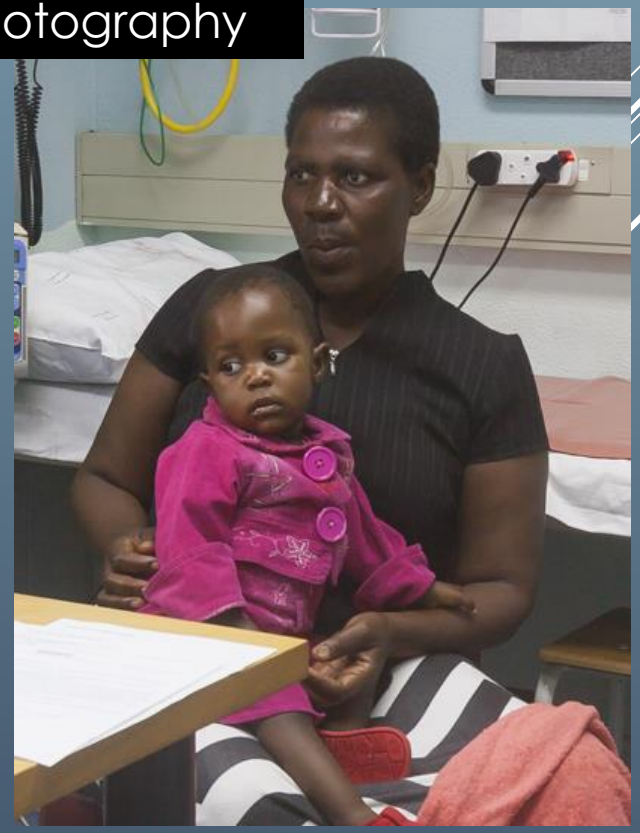


DEVELOPMENTAL VARIABILITY OF THE CHILD PATIENT'S REACTIONS

- Baby under 6 months

  responds to comforting reassurance

- Age of stranger anxiety

  mother's presence imperative

- Toddler and young child

  intense emotions: screaming and fighting gives way to withdrawal

  Serious sign : rhythmic head banging, rocking

Illness and weakness are superimposed on these typical patterns of behaviour

DEVELOPMENTAL VARIABILITY OF THE CHILD PATIENT'S REACTIONS

- The young child takes its cues from its mother's emotions and reactions : often seen to look at mother's face before reacting

For the child, mother "knows all"; therefore to see mother frightened or disturbed is often profoundly threatening.

Children listen in on the conversations

- Adolescents are fixated on the present, on body image, on need for "normality", on guilt. Cannot process abstract thinking like an adult

Illness, weakness, fear and loneliness are superimposed on these typical patterns of behaviour

THE PATIENT / FAMILY NEEDS OF CARE BEYOND MEDICINE

- Need for information to allow meaningful participation in decisions

  Mother: I do not know why I have been referred here from …

  Feel left out, therefore no appreciation of the need for commitment to our care eg compliance

- Need for patient (family) autonomy and responsibility

  Empowered to make appropriate informed decisions

  Empowered to embark on meaningful faith-based or social rituals

THE PATIENT / FAMILY NEEDS OF CARE BEYOND MEDICINE

- Need for honesty

  Patients recognise falsehoods; this undermines trust

- Need for trust

  Must trust enough to be able to tell us even if they have gone against our advice

  Two-way street of trust: we should not express doubt or disbelief

- Need for hope

  For recovery/ improvement/ relief of suffering

These have major implications for counselling

THE DOCTOR'S NEEDS

- Need for affirmation and respect

Vulnerable when patient chooses another doctor/ hospital or alternative/complementary medicine, faith healing or traditional rituals

Emotional investment

- Need for ongoing learning

Growth as a professional and as a human being

- Need for humility

We may see our contribution to the patient's care quite differently to the patient or family

- Need for honest feed-back

Medical success does not necessarily translate into human success

Doctor-Patient Dyad

In a way, this is a contractual commitment:

- Cure or recovery
- Prolong life
- Help or ameliorate symptoms

Cure or recovery is not possible in terminal disease. Prolonging life in a way also prolongs suffering and thus it is possible to do harm with treatment.

There is a place for honest appraisal and positive decision for palliation and symptom control

Organ replacement therapy is one option in this scenario, BUT no transplant recipient stops being a patient

DOCTOR-PATIENT "CONTRACT"

Primum non nocere : above all: do no harm!

This has implications for counselling and management decisions in serious incurable disease such as cirrhosis: need to balance realism with hope, but not offer false hope

Active treatment, palliation, withdrawal?

BUT consider carefully: Who decides, on whose standards?

The mention of transplantation may engender unrealistic hope

- Consider qualification first
- No transplant recipient stops being a patient

THE DOCTOR-PATIENT "CONTRACT" CHANGES

"Do no harm" extends beyond the physical patient

Initially, we seek to:

- Cure or aid recovery
- Prolong life
- Help or ameliorate symptoms

The aim is restoration of life

In the last stage, we seek to:

- Help or ameliorate symptoms
- Reduce the physical and emotional suffering of dying and death

The aim is to make death a little easier

MANAGEMENT DECISIONS IN CHRONIC DISEASE

- *Medical knowledge and insight*

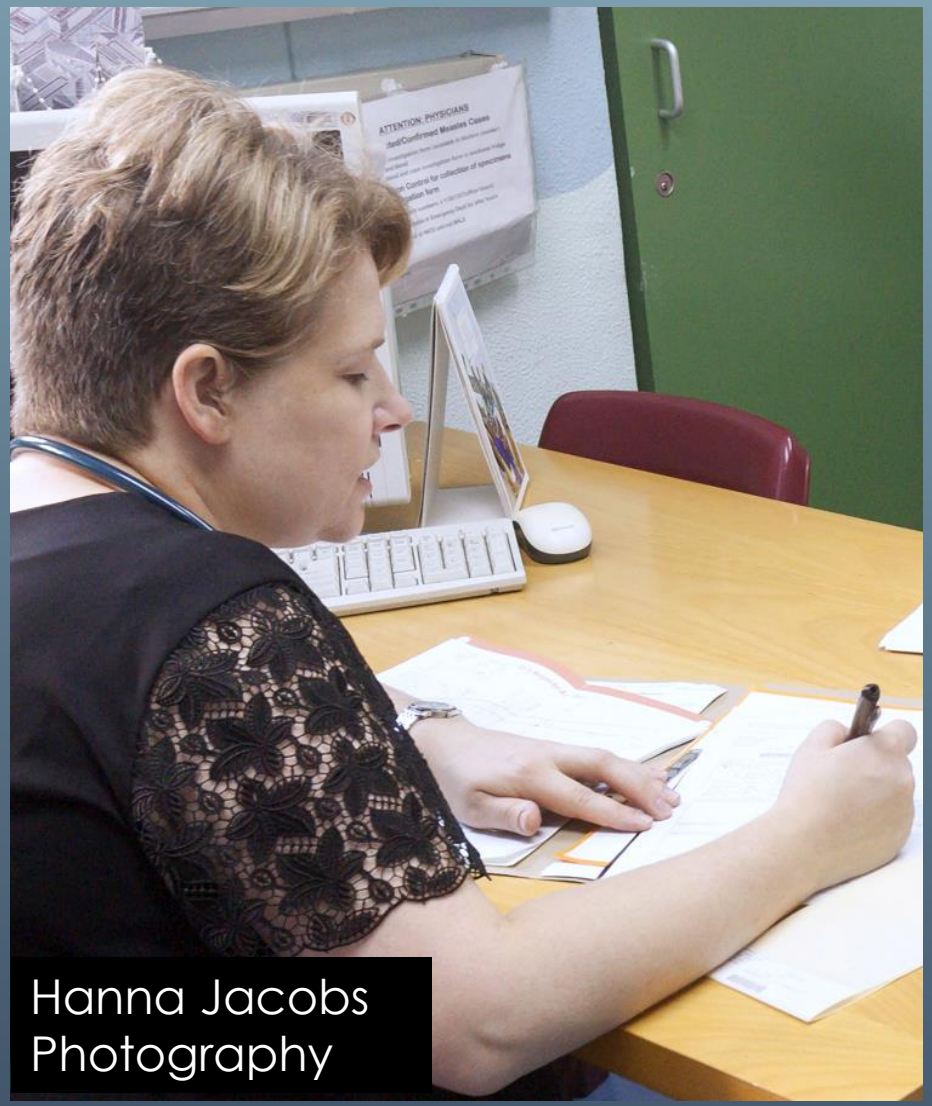
Disease stage, progression and outcome

- *Teamwork*

Multiple specialist inputs and team decisions

- *Family dynamics, needs, belief systems, resources*

Essential member of the healthcare team



Particularly in chronic disease, doctors have a unique opportunity to play a meaningful supportive role in the patient's and family's life