Strategies to improve patients experience in community end of life care

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I’ve learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel

Maya Angelou

Aims

- The relationship of the patient, the illness and the healthcare worker within a community palliative care service
- Process in developing a patient centred approach in end of life care
- Overcoming challenges to improve outcomes

Hospis Malaysia

Duration of care

Patients Duration of care	0-7 days	8 – 14 days	15 – 29 days	30 – 89 days	90 – 179 days	Over 180 days
2020 (%)	26.3	16.96	19.44	26.72	8.35	2.23
2019 (%)	21.79	14.48	18.24	28.29	10.71	6.5
2018 (%)	21.43	12.75	19.58	26.20	10.17	9.76

The practice of medicine is an art, not a trade; a calling, not a business; a calling in which your heart will be exercised equally with your head

William Osler 1903

Palliative Care as more than ‘damage limitation’

Beyond symptom control, I began to realise, as I listened to patients, that I was seeing something of their **potential for making achievement** of this part of their lives

Cicely Saunders 1989

Palliative Medicine…just another specialty ?

It is argued that palliative medicine may be in danger of developing into a specialty of 'symptomatology'. Such a specialty would be confined by the limits of the medical model and its particular view of illness.

M Kearney Palliative Medicine 1992

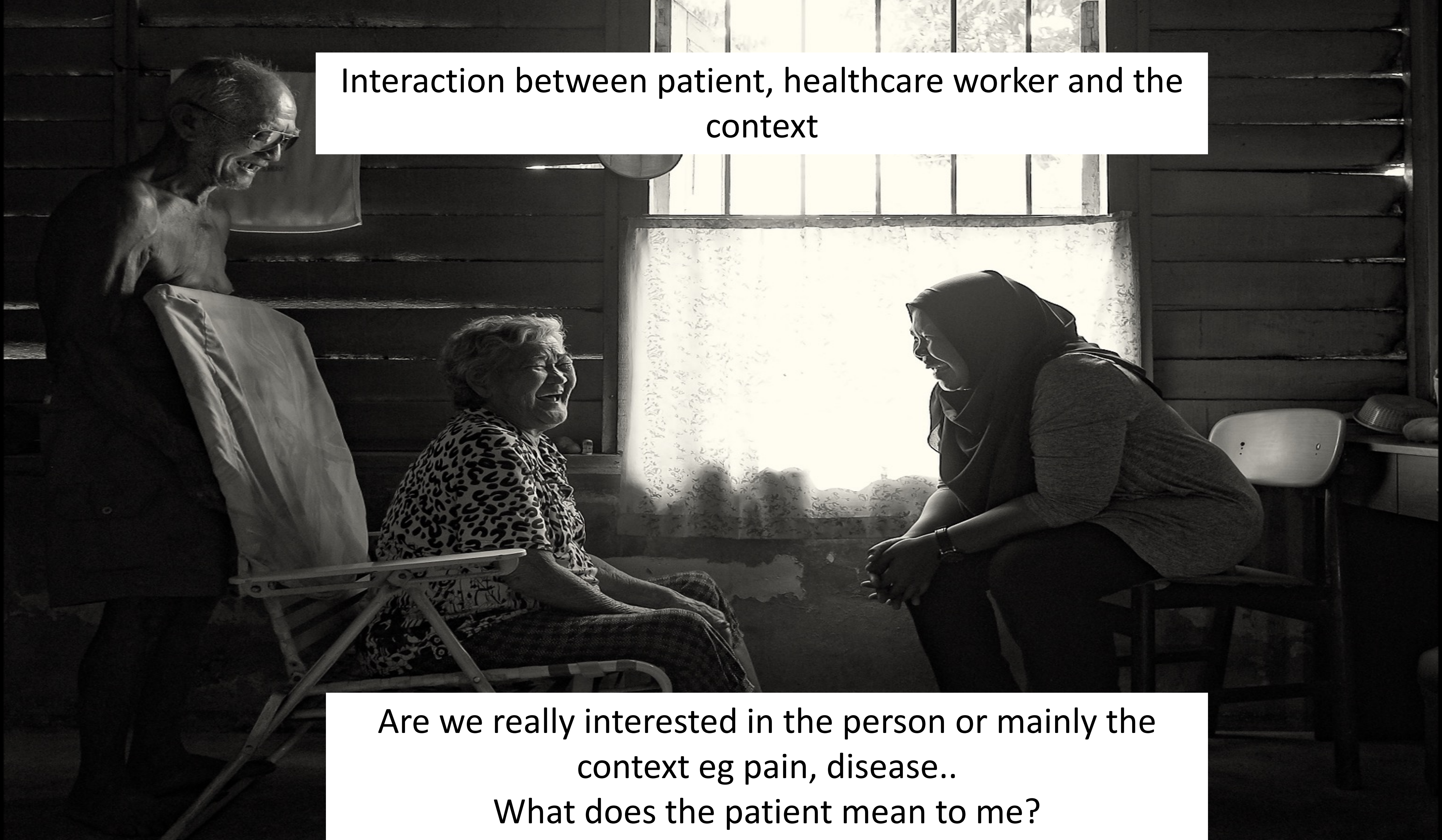
Chronic niceness syndrome!

- People doing palliative care are nice people!
- They don’t want to upset anyone?
- This may lead to a compromise on
  - Communication
  - Avoidance behaviour
  - Clinical examination
  - Ethical issues
  - Standards

Who am I ?

- What do I bring to the patient and the family?
- What attitude do I bring?
- What are my values and how will they be affect by other values that may be different?
- What knowledge and skills do I have and how relevant are they in the situation?
- What outcomes do I seek?

Interaction between patient, healthcare worker and the context



Are we really interested in the person or mainly the context eg pain, disease..
What does the patient mean to me?

Stances

I.

Placating

II.

Blaming

III.

Super Reasonable

IV.

Irrelevant

Virginia Satir

Congruence

Congruence

- To move to engage the patient, beyond both blaming and placating to include ourselves and the patient fully in the relationship
- Congruence is a learned process that will be different in every patient physician relationship

Satir V et al. The Satir Model : Family Therapy and beyond 1991.

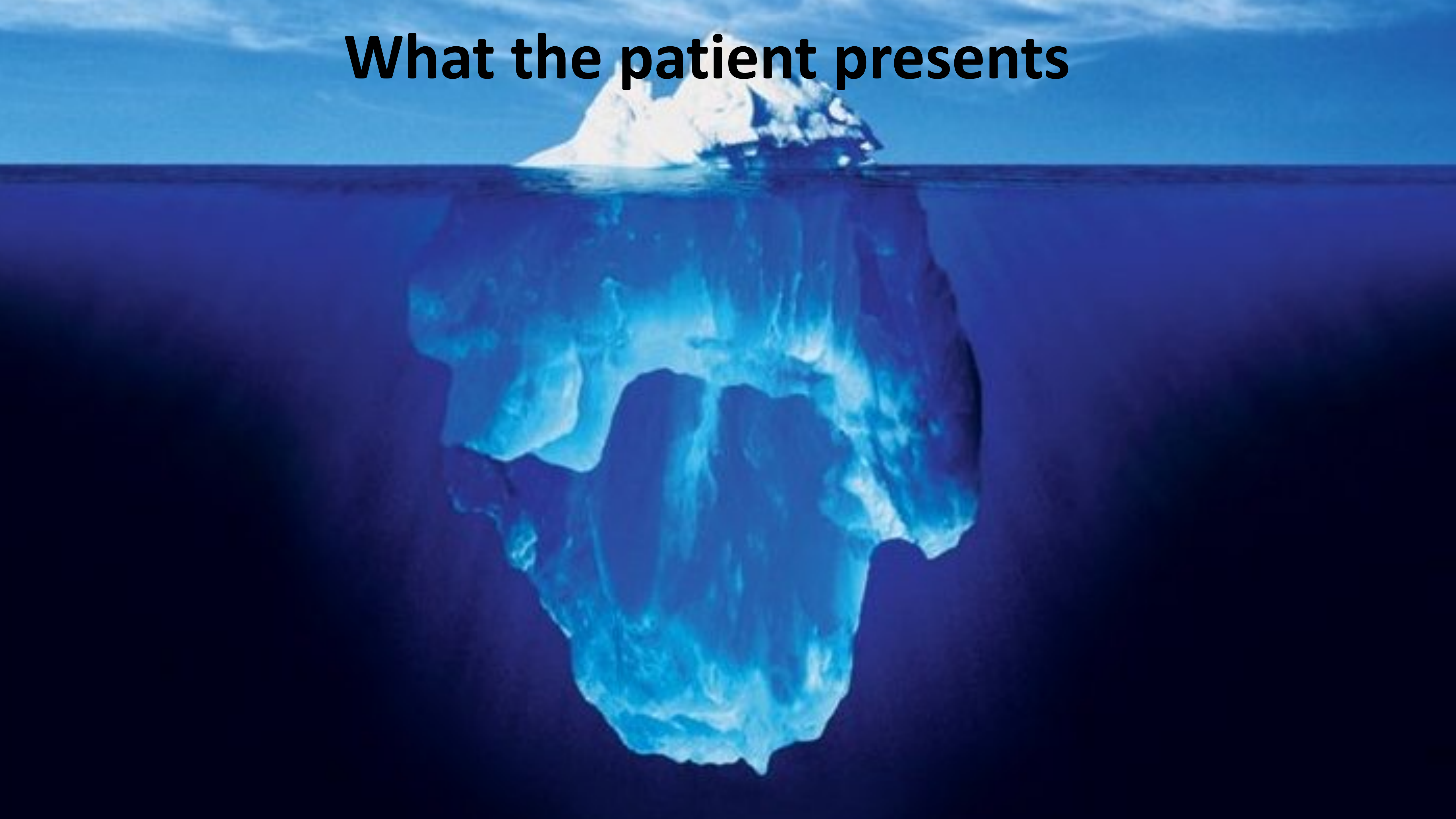
Affect on providing care

- Healthcare workers may use their cultural identification to manage their own unconscious anxieties
- Affect clinical decision making
- Adhere unquestioningly to the medical culture in which they trained and practice
- Easier to think of patient as ‘other’ rather than embrace both theirs and our own vulnerability and mortality

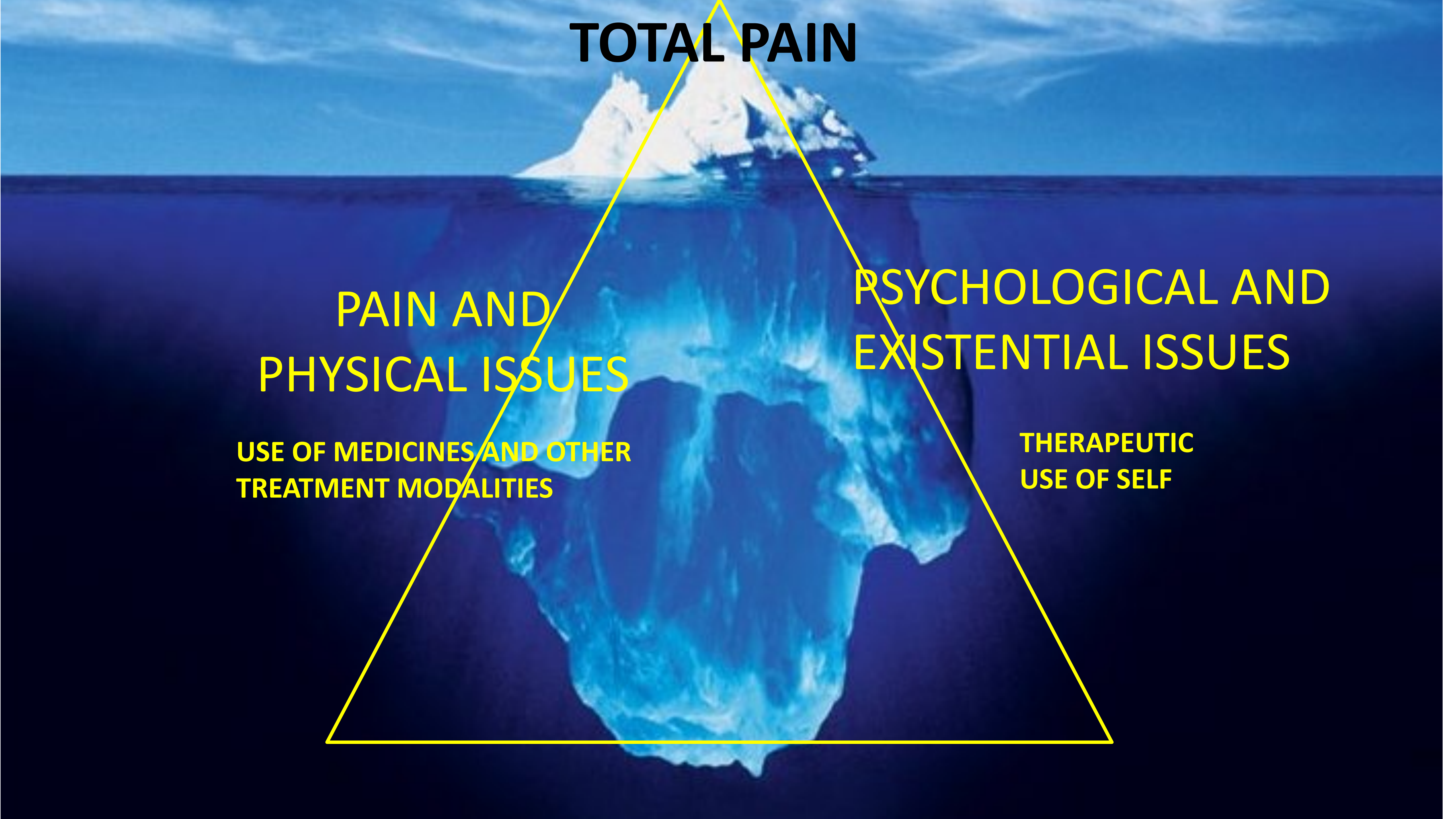
Who is the patient and what are his / attributes ?

What does the patient bring to the encounter with you?

What the patient presents



TOTAL PAIN



PAIN AND PHYSICAL ISSUES

USE OF MEDICINES AND OTHER TREATMENT MODALITIES

PSYCHOLOGICAL AND EXISTENTIAL ISSUES

THERAPEUTIC USE OF SELF

Questions for a Community palliative Care service?

- Is each person seen as an individual?
- Can all that need palliative care be able to access care?
- Are we able to address all aspects of their suffering?
- How can comfort and wellbeing be maximised?
- Can we make them feel safe under our care?
- Coordination within organisation and other agencies
- Is everyone within the service willing to care?
- Is there external community support?

Patient centred care

Providing care that is respectful of and responsive to individual preferences, needs and values and ensuring that patient values guide all clinical decisions

Dimensions important for patient centred care

- Respect for patient values, preference and expressed needs
- Provision of information and education
- Access to care
- Emotional support to relieve fear and anxiety
- Involvement of family and friends
- Continuity and secure transition between healthcare settings
- Physical comfort
- Coordination of care

Gerteis M det al. Through the Patient’s eyes: understanding and promoting patient-centered care. 1993.

- However, the relative importance of these dimensions may be different to the healthcare professional and family
- Understanding such differences may be important as it may translate into different priorities and delivery of care

Patient centred care

- Requires ‘cultural’ shift from health care workers
- Changes the role of a patient from a passive to an active participant
- Services derived from patient needs and what they value
- Creates a system that is better engaged, greater satisfaction and hopefully more clinically efficient

Outcomes in patient centred consultations

- Health improves
- Patient satisfaction
- Less concerned about problem
- Adherence to treatment
- Lifestyle changes

Place of Death

	Home	Hospital	Nursing home	Others
2020 (%)	71.26	25.03	3.01	0.7
2019 (%)	65.69	28.86	4.86	0.59
2018 (%)	62.45	31.69	5.34	0.52

Factors affecting preferred place of death

- Preference – the basis for the preference
- Previous experience – at home and hospital
- Symptom control
- Care givers acceptance and coping skills
- Supportive care
- Cultural factors

- Good community palliative care is best to address the above issues
- Addressing the above issues improves patient / caregiver experience

Cultural competence

An examination of ones own attitudes and values, and the acquisition of the values, knowledge, skills and attributes that will allow an individual to work appropriately in cross cultural situations

Denboba 1993

Cultural competence

Patients live in the community and try to cope with illness and suffering

Healthcare workers live and train in hospital environment with minimal awareness of coping with illness in the community

Setting up to fail?

It can be challenging to accept the validity of another persons narrative….not impossible

Community visits

- Requires additional skills from hospital care
- Patients and caregivers seen in their home environment
- Home provides additional clues in assessment
- Higher reliance on clinical skills than technology
- May affect clinical decision making

A typical Medical consultation

- Greeting and relating
- Discovering the reasons for attendance
- Conducting a verbal or physical examination or both
- A consideration of the condition
- Detailing further treatment
- Terminating the interview.

Byrne and Long, 1976

Power of medical language

- Goal seeking
- Illicit information
- Control the progress of the consultation
- Unequal balance of power between patient and doctor

‘The doctors understand cancer, they don’t understand me’

Azlin

Spontaneous talking

- Opening statements?
- Controlled versus spontaneous speech
- Average time patient allowed is **22** sec before doctor takes over
- Mean spontaneous talking time was **92** sec and 78% had finished their opening statements in 2 mins
- Doctors felt that the information contained was valuable and the patient should not be interrupted

Langewitz w et al . BMJ 2002

Patient Dignity Question (PDQ)

What do I need to know about you
as a person
to take the best care of you that I can?

Framing question to illicit information on how the patient is perceives the situation and potential coping interventions

- Are you the same person you used to be ?
- Have you lost your place in life?
- Is there anything you are looking forward to?
- Are you in control?
- What are you proud of?

Patient Dignity Question

What do I need to know about you as a person to give you the best care possible?”

- Improve patients perception of care
- Improve healthcare professionals attitude
- Improves assessment and address areas which may not have been noted
- May be challenging to use
- Requires good communication skills

Johnson et al BMC Palliative Care 2015

McIlfatrick et al J Clin Nurs 2017

Wafa Abdul Kadir

2 short narrative about her diagnosis and the uncertainly that cancer brings

She had advanced ovarian cancer with significant complications including very severe pain and intestinal obstruction

She was an actor and has a supportive family

Listen to the patient's narrative

If God wills that I have cancer, god has said "Be, and it is" that means it will happen.

Telling their story allows the patient to:

- To frame their narrative of their illness
- Interpret factual data into an expression
- Illustrate the impact of their illness to their lives
- Convey their values through the narrative
- Express fears and anxieties in a safe way
- Express yearning of hope even though it may not likely be achievable
- Allows acceptance of the present

Listening : paying attention

Listen to what is being said and not just hearing

Listen to understand and not just hearing

Listen to the context, values and emotions that are within the message

The patient’s narrative

- Aspects of relationship
- Cultural and religious perspectives
- Hopes and yearnings
- Secrets to be uncovered, shared or left alone..
- The importance of legacy

Benefit to clinician

- Allows for a more accurate diagnosis
- Understands problems in context
- Allows a more contextual framing of possible options
- Opportunity to probe further in areas of relevance to both
- Starting the transformative process that could facilitate healing

Consultation within a conversation

- The person as the focus rather than the disease
- Allow the narrative to flow
- Show interest and clarify the reasons and values that underpin decisions taken
- Emphatise and reframe
- Find opportunities to probe relevant areas
- Use questions that require positive statements rather than just illicit problems and symptoms
- Appropriate humour

Patient Values vs Doctor Values

What is important to the doctors (health outcomes)

≠

What is important to the patients (personal values)

Ethical communication

- Stereotyping – perceived choices, behaviour
- Language
- Judgemental
- ‘Blaming’
- Respectful of patient’s views
- Bias
- Power distance

Be curious

- Healthcare workers often look out for signs and symptoms that offer clues to disease process
- In dealing with aspects of quality of life, be curious about :
    - The value of relationships that matter to patients…including pets
    - Objects of values eg pictures, souvenirs that are often a link to past memorable moments
    - Cultural symbols that may reflect on important values or traditions
    - Alternative healthcare treatments that may reflect hopes

Presentation of pain or other issues

Patients may present their issues differently to different people and in different locations

Caregivers can only give their perception of the patient’s pain. It may not be an actual representation

There may be a tendency to believe the caregiver rather than the patient..?

In asking about pain

- Don’t just focus on the factual nature of the pain?
- Consider enquiring about :
  - How does the pain affect your living?
  - How would someone else recognise when you are in pain?
  - What could I do that would be helpful?
  - Tell me more?

Making decisions?

Pitfalls

- Cultural competence / congruence that may affect decision making process
- Making assumptions and creating expectations
- Ethical issues

We do not know how to ask
for something that
we do not know about

patient

Conceptual thinking

- It is not easy for patients to visualise a potential future healthcare intervention
- May draw references from others or media portrayal
- Increase accurate information will help
- Be aware of the difference between a conversation and a binding decision

Caregivers

- Mainly female
- Domestic helpers
- If working, this will be affected which may have consequences
- Psychological effects both positive and negative
- Sleep disturbance, weight loss and fatigue are common

Using the CARES framework

- **C**onsider caregivers as part of the unit of care
- **A**ssess the caregivers situation, perception and needs
- **R**efer to appropriate services and resources
- **E**ducate about practical aspects of caregiving
- **S**upport caregivers through bereavement

Caregivers

- Caregivers often feel inadequately prepared
- Impact on emotional state
- Unsupported, unprepared, overwhelming responsibility
- 66% refused to provide analgesics
- Stop analgesiscs when pain controlled
- Face to face teaching supported by written or other resources increase knowledge and efficacy

Latter S et al. BMJ Support Palliat Care 2016
Mehta A et al. J Psychosoc Oncol 2014

Important domains for patients and families

- Physical comfort and symptom control
- Control of decision making
- Education and emotional support
- Not having prolonged death, being prepared
- Holistic individual care
- Caring for loved one at home but challenging caregiver experience
- Effective communication and appropriate information

Reasons for out of hours calls

- Symptoms – 53%
- Medication query : 7%
- Equipment – 10%
- Death – 11%
- Others – 19%

Patient reported outcomes

- Hospis Malaysia uses the Edmonton Symptom Assessment Score (ESAS) to score severity of symptoms since 2019
- However many patients are too ill and unwell to complete them regularly
- Given the short prognosis of many patients, the score of symptoms such as fatigue, appetite and wellbeing are unlikely to improve
- However, improvement in other symptoms are important and will affect the ability of patient and caregiver at home
- Discussing patient outcomes may allow symptoms that are ‘less’ apparent yet may be very distressing to be addressed

Issues around grief and loss

- Anticipatory grief
- Managing the loss of a loved one
- Unfinished business
- Legacy
- Challenging when patients are referred late and virtually impossible when hospitals insists on TERMINAL DISCHARGE policies!
- All worse during the Covid 19 pandemic

The good death?

Is there a possibility that rather than explore a person’s perspective on end of life, we start to prescribe our bias ?

Community challenges

- Lack of professional and specialist support structure
- Financial issues
- Competing demands in primary care
- Limited public understanding of palliative care
- Issues with medication – even in hospitals
- Communication skills

Community palliative care

- Referrals often / usually late
- Doctors / hospitals do not know what a community palliative care service provides
- Patient / family expectations
- Lack of resources to deal with complex situations
- Significant number of patients **DO NOT WANT** to go to hospital (under any circumstances !)

Summary : Emotional experience in care

- Respect – allowed expression, empathy, acceptance, recognition, listened, prioritised as a person yet incorporated with others , responsive, fulfilling patient’s wish
- Renewal – changes in attitude, increased confidence, renewed agency, being able to cope , recognition that illness affects the whole family
- Refuge – place of safety , ability to express fears that cant be done elsewhere , expertise and responsiveness coupled by warmth and sensitivity , managing transitions and negotiate uncertainty
- Restorative – allows relaxation or enjoyment, body as normal instead of diseased, intimate care of the body

Conclusion

- Living with a life limiting illness has a devastating effect on the patient and family / caregivers
- Providing patient centred care requires a significant investment and real interest in a person as well as the illness experience
- A significant ‘cultural / attitudinal’ shift is required from those who are more at ease in hospital surroundings
- A supportive framework of community palliative care services including out of hours and bereavement support is important
- A reflective learning process allows greater attentiveness to potential issues
- Improving symptom control in all domains will improve patient and family experiences
- Regard the patient and their family / caregivers as our teachers and guides