Patient-Centered Communication: Rhetoric or Reality

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What is patient centeredness?
Patient - centredness

- “Understanding the patient as a unique human being”
  - Edith Balint 1969

- “A style of consulting where the doctor uses the patient’s knowledge and experience to guide the interaction”
  - Byrne & Long 1976
Patient - centredness

• “The physician tries to enter the patient’s world, to see the illness through the patient’s eyes”
  
  McWhinney 1989

• “Closely congruent with, and responsive to patients’ wants needs and preferences”

  Laine & Davidoff 1996
Is it so important?

• “Just as the molecular and chemistry orientated sciences were adopted as the 20th century medical paradigm, incorporation of the patients perspective into medicine’s definition of patient need has been suggested as the medical paradigm of the 21st century”

Deborah Roter 2010
Patient-centered Communication

- Refers to communication among clinicians, patients and family members that supports patient-centeredness
  
  - Eliciting the patient’s perspective
  - Understanding the unique psychosocial context
  - Reaching a shared understanding concordant with the patient’s values
  - Helping patient to share power

Epstein et al 2005
Patient – centred communication

- Key dimensions
  - Biopsychosocial rather than biomedical model
  - Patient as a person … individual experience
  - Sharing power and responsibility rather than paternalistic
  - Forming a therapeutic alliance
  - Doctor as a person

Mead & Bower 2000
Is it what patients want?
Research evidence indicates that a ‘willingness to listen and explain’ is considered by patients to be one of the essential attributes of a health professional, along with sensitivity, approachability, respect and honesty.’

The NHS Cancer Plan (2000)
Feedback from Patients

Patients value

• Being asked open questions about themselves
• Permission seeking
• Partnership statement shared decision making
  Cousin et al 2012
• Being included in the conversation
• The doctor getting to know the patient personally
• Continuity and consistency
• Feeling the professional has time
• Clear and sensitive sharing of information
• Attention to issues beyond the physical
• Doctor being empathic and humane
  Janssen & Macleod 2010
Feedback from Patients

Patients give priority to:

• being treated with *humanity, dignity and respect*
• having *good communication* with health professionals
• being given *clear information* about their condition
• receiving the *best possible symptom control*
• receiving *psychological support* when they need it
What patients want/need …

An NHS that gives patients and the public more information and choice, works in partnership and has quality of care at its heart.

- Tackle variations in quality of health care head on
- Give patients more information and choice
- Give people a greater degree of control and influence over their health and healthcare.
- Make care more personal to each individual
- Make change locally-led, patient-centred and clinically driven

Lord Darzi - High Quality Care For All - 2008
Are there any benefits?
Patient benefits …

- Medical Specialists facilitating behaviour was associated with higher satisfaction in patients.  
  Zandbelt et al 2006

- Cue responding related to patient satisfaction.  
  Uitterhoeven et al 2009

- Distancing from emotional cues significantly impacted on recall of information p=0.002. 
  Nurses response to informational cues not related to recall.  
  Jansen et al 2010
Patient benefits …

• Patients who consultations were rated as relationship building had better treatment effects at 6 months  
  
  Dibbelt et al 2009

• Patient centered communication linked to
  • Increased satisfaction
  • Adherence to treatment
  • Improved self management

  Levinson 2010; Charlton et al 2008
Impact of communication

- Fear, Isolation, confusion and distress
- Adherence to treatment and increased admissions
- Quality of life and psychological morbidity
- Satisfaction with care, complaints and litigation
- Guilt, confusion and isolation in relatives
- Burnout in healthcare professionals
Is it Rhetoric or Reality?
What people approaching death say about patient centered care?

• “When they are talking to you, you are the most important person to them. They try to find out what makes you tick, what makes you cry your eyes out, that sort of thing. They send out this “I really care what happens to you’ ..”

  Janssen & MacLeod 2010

• “The first really good thing was the first question they asked him. It was “what do you actually want? What he wanted was to back to his own flat. They said …we’ll see if we can make it possible. He got back to his own flat. He only lived 6 hours, but he died happy”

  Finding the words; patients and families view of communication 2011
What people say about patient centered care?

• “The Oncologist said ‘tell me about yourself’ … I was so stunned because nobody had ever said that … you are usually just a melanoma or a bunch of symptoms’ ..”
  Janssen & MacLeod 2010

• “The doctor took the time to sit and listen …. He sat down long enough to get all of my questions answered”
  Swayden et al 2012
“They were all very nice, very wonderful, but I realised afterwards that nobody told me anything.”

Female breast cancer patient
National Cancer Alliance (1996)
What people approaching death say about patient centered care?

- “I have stopped expecting them to know about how to treat patients … so I am teaching them”

- “Obviously they (the doctors) had trouble with the “C” word … you don’t have to have a degree in nuclear physics to work it out… say what it is..”

- “He just left the room ….. we looked at each other. That was quite sad…. Your mind is going so fast you are new to the game, you couldn’t absorb it…”

Janssen & MacLeod 2010
What other patients say about patient centered care?

- The consultant came to talk to me as he did every few days ..... He asked me “how are you today?” …

  Although he was asking “how are you” … I knew what he actually meant was…. “how is your tumour” …

  *Brain tumour patient - Jimmy Teens TV 2008*
National reports - UK

- Department of Health Cancer Plan (2000)
- NICE Supportive and Palliative Care Cancer Service Guidance (2004)
- Cancer Reform Strategy (2007)
- High Quality Care for All – NHS Next Stage Review, Lord Darzi (2008)
- End of Life Care Strategy (2008)
- Improving Outcomes Guidance (2011)
National reports – New Zealand

• The medico-legal framework includes features relevant to communication skills training.
• The Code of Health and Disability Consumers’ Rights promotes patient choice and autonomy in health care.
  • Dignity and independence (Right 3)
  • Services of an appropriate standard (Right 4)
  • Effective communication (Right 5)
  • Be fully informed (Right 6)
  • Make an informed choice and give informed consent (Right 7).
• Better sooner more convenient 2007
• The New Zealand Cancer Control Strategy (2003)
• Guidance for Improving Supportive Care for Adults with Cancer in New Zealand (2010).
Government messages …

- Targets are what the hospital is measured on
- Financial management measured by cost savings and doing more for less
- Efficiency is about
  - Throughput of patients
  - Shorter stays
  - More patients seen
<table>
<thead>
<tr>
<th>Key complaints</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Safety of clinical practices</td>
<td>22%</td>
</tr>
<tr>
<td>2. Poor communication / insufficient information</td>
<td>16%</td>
</tr>
<tr>
<td>3. Ineffective clinical practices / admin procedures</td>
<td>5%</td>
</tr>
<tr>
<td>4. Poor handling of complaints</td>
<td>5%</td>
</tr>
<tr>
<td>5. Discharge and co-ordination of care</td>
<td>4%</td>
</tr>
<tr>
<td>6. Lack of dignity and respect</td>
<td>4%</td>
</tr>
<tr>
<td>7. Poor attitudes</td>
<td>4%</td>
</tr>
<tr>
<td>8. Failure to follow agreed consent procedures</td>
<td>4%</td>
</tr>
<tr>
<td>9. Poor environments, poor hygiene</td>
<td>3%</td>
</tr>
<tr>
<td>10. Lack of access &amp; disputes about clinical records</td>
<td>3%</td>
</tr>
</tbody>
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UK Healthcare Commission 2007
Complaints and litigation

- 90% complaints dealt with by official bodies concern poor communication
- 30-40% of patients who have begun litigation, do not proceed if they receive an adequate explanation and apology
- Lack of sensitivity of doctors is often a significant factor leading to lawsuit

Listening to patient concerns

• over 50% of concerns missed during bad news consultations  
  Green et al 2006

• nurses failed to recognise 80% of chemotherapy patient’s concerns  
  Farrell et al. 2006

• Oncologists fail to identify majority (70%) of patients with probable psychiatric morbidity (despite being assessed)  
  Fallowfield et al 2001

• Less than half of those patients identified as depressed through screening had been identified and treated  
  Sharpe et al 2004

• up to 60% of concerns remain undisclosed even in a hospice setting  
  Heaven & Maguire 1998
Importance of negotiated decision-making

• Associated with increased patient satisfaction
• Third of newly diagnosed cancer patients fail to achieve their desired level of involvement  
  Gattellari et al 2001

• Breast cancer patients who shared decision-making had better quality of life three years later  
  Hack et al 2005

• New information may alter a patient’s preference  
  Butow et al 1997

• 64% of oncologists failed to recognise patients’ wishes  
  Rothenbacher 1997
Giving Information in a sensitive way

• Only a small proportion of patients receive the information they require  
  Hinds et al 1995

• > 25% palliative care pts not told disease incurable and 33% patients believe palliative regimes are curative  
  Dias et al 2003

• Oncologists only answer 33% of patients questions.  
  Butow et al 1995

• Yet; more than 85% patients want full information, good or bad.  
  Jenkins, Fallowfield & Saul (2001)
Problems with style / approach

• What patient’s want to discuss and what is actually discussed in end-of-life conversations, often differs
  
  Street and Ottmann 2006; Lyon 2007

• Literature shown that medical students tend to loose patient centered attitudes as they progress through medical school
  
  Hojat et al 2009; Bombeke et al 2011
## Micro skills level ....

<table>
<thead>
<tr>
<th></th>
<th>English Nurse specialists</th>
<th>Dutch Oncology nurses</th>
<th>Dutch Oncology Nurses</th>
<th>Dutch oncology Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledge</td>
<td>Real patients</td>
<td>Simulated patients</td>
<td>Real patients</td>
<td>Real patients</td>
</tr>
<tr>
<td></td>
<td>30.7%</td>
<td>17%</td>
<td>24%</td>
<td>29.5%</td>
</tr>
<tr>
<td>Explore</td>
<td>10.4%</td>
<td>33%</td>
<td>21%</td>
<td>34.7%</td>
</tr>
<tr>
<td>Distance from</td>
<td>56.9%</td>
<td>50%</td>
<td>55%</td>
<td>35.8%</td>
</tr>
</tbody>
</table>

Heaven et al 2008; Uitterhoeven et al 2008; 2009, Jansen et al 2010
Are we cue focused…

- Drs unobservant of emotional cues, despite the fact that there was no increase in patient anxiety if picked up
  
  Butow et al 1995

- Oncologists keep questions to bio-medical probing
  
  Ford et al 1996

- Drs respond to 20-40\% of emotional cues (GPs and surgeons respectively)
  
  Levinson et al 2000
BUT ....

We’ve been teaching patient centered interviewing ...
Training studies

Communication skills training that includes role-play can change health professionals’ attitudes and behaviours

  - Randomised trials of groups of nurses
  - Pre/post design. Single and multi-professional groups of cancer professionals
- Fallowfield et al 2002
  - Randomised trial of oncologists (n=160)
- Wilkinson et al 2008
  - Randomised trial of oncology nurses (n=172)
Communication skills training

- Now integrated into the medical and nursing curriculum in the majority of countries
- Examined in OSCE medical student examinations
- Examined in medical postgraduate college fellowship examinations
- Mandatory in some spheres for specialist clinicians
So what’s going wrong ?
The Goal posts have changed ...

Social factors
- Aging population
- Literacy levels
- Internet

Medical factors
- Cure culture
- Patients care is fragmented
- Complexity of prognostication
Organ failure, long term limitations, acute episodes

Short period of evident decline, typically cancer

Prolonged dwindling
Barriers

Fears
- Unleashing strong emotions
- Upsetting patients/relatives
- Patient refusing treatment
- Difficult questions
- Damaging the patient

Beliefs & Attitudes
- Emotional problems are inevitable
- Not my role
- Talking raises expectations
- Patient will fall apart
- Will take too long
- I should not admit failure
- There is a specific way to do this
Acknowledging failure

“And if you actually have to go and talk to somebody about your failure to cure them, that is also putting you, yourself, in a different position that is difficult to cope with. It takes time and it burns me up, I come away exhausted.”

Rosser & Maguire, 1982
Barriers…

Lack of skills
- Assessing knowledge and perceptions
- Integrating elements of the consultation gathering and giving
- Handling difficult reactions
- Insufficient command of the language
- I don’t understand their culture

Working environment
- No support or supervision
- No referral pathway
- Staff conflict
- People being present
- Lack of time
- Privacy

Maguire, 1999; Booth, et al., 1996; Wilkinson, 1991
Cultural difference

- Evidence for cultural differences impacting on information needs inconclusive
- Important not to make assumptions about patient’s needs based on culture
- Doctors worldwide underestimate information needs of patients
- Doctors and nurses cultural differences guide behaviour

Pressure to problem solving …

- Move into fixing the problems we can do something about
  - It feels good to do something
  - We are here to care and help

- Avoiding those things we know we can do nothing about
  - It is inevitable that people feel like this, talking cannot change anything  
    Newell et al 1993
  - Nothing can be done about mood disturbance  
    Gask et al 2005
Communication skills training

• Students training in communication skills slightly but significantly decreased in patient centered attitudes
  • Gap between ideal training and real world
  • Validity of the measures

Bombeke et al 2011
Hard using skills in different or new situations…
Communication skills training

• Students training in communication skills slightly but significantly decreased in patient centered attitudes
  • Gap between ideal training and real world
  • Validity of the measures Bombeke et al 2011

• Drop in provide space responses from 60% to 40% between year 1 and year 2
  • OSCE scores significantly negatively correlated with cue responses

Cherry (Unpublished)
Transfer ....

The degree to which trainees **effectively apply** the knowledge, skills and attitudes gained in a training context **to the job**.

For transfer to have occurred learned behaviour must be **generalised** to the job context and **maintained** over a period of time

Baldwin & Ford 1988
A Model of Transfer

Training inputs
- Trainee characteristics
  - ability
  - personality
  - motivation
- Training design
  - Learning Principles
  - Sequencing
  - Training content
- Workplace environment
  - Support
  - Opportunity to use

Training outputs
- learning
- retention
- generalisation
- maintenance

Transfer

Baldwin & Ford 1988
Trainee characteristics

- Personality - how respond to challenge
- Motivation
  - Energising, directing, maintaining
  - Expectancy about ability to master content
  - Expectancy about rewards from mastering content
  (Noe & Schmitt (1986))
Transfer Enhancing Training ...

- Identical elements ... Matching of training to reality
- Underlying principles ... Must be addressed
- Stimulus variability ... Several stimuli
- Whole vs part ... Focus on the totality helps
- Grouped vs extended ... Training over time
- Feedback on performance ... Critical element
- Over learning ... Practice beyond mastery

Baldwin & Ford 1988
Workplace environment

• Attitude of trainees manager to new skills ..
  • Support the decision to train
  • Support the student in trying new things / ideas
  • Help ‘buffer’ the inhibitory and facilitative factors
    • Workload
    • Autonomy

Huczynski & Lewis 1980
Timing

• Timing
  • The decision to use newly acquired skills occurs during first 24hrs in the workplace
    • Work overload
    • Crisis
    • Colleague scepticism
  • The longer the decisions making period the less likely it is to be positive

Huczynski & Lewis 1980
Theories ...

• Marx 1982

• Whilst coping successfully with difficult situations increases one’s sense of mastery, mastery of complex skills is a trial and error process requiring monitoring and coping skills. Improvement is usually a gradual.

• For many trainees, the inability to attain rapid result immediately will result in a decreased expectation in the ability to master the skill and a decrease in self efficacy.
Theories ....

• Bandura’s social cognitive learning theory
  • “Individuals with strong beliefs in their ability to perform a behaviour successfully with a positive outcome are more likely to initiate the behaviour and persist through difficulties”
    • Self efficacy
    • Outcome expectancy
    • Mastery of the skill
    • Support
Model of communication
Parle, Maguire & Heaven 1997

Skills & knowledge

Self-efficacy

Outcome expectancy

Perceived support
- personal
- professional

Communication behaviour
Theories ....

- **Optimality Theory** *(Prince & Smolensky 1993)*
  - Those behaviours which are seen as optimal in achieving the end goal

- **Action Assembly Theory** *(Green 2008)*
  - Learnt actions and reactions from many conversations over time

- **Communication Accommodation Theory** *(Giles 2008)*
  - Convergent – matching behaviours
  - Divergent – desire to accentuate difference
Organisational factors ....

• Are hospital systems really set up to allow for truly patient centered care
  • Flexibility in appointments and admissions
  • Time for thinking and choices
  • Relatives being involved and talked to
  • Flexibility and choice in who we see and where we see them
• Patient centered philosophy not integrated into clinical research (Smith 2011)
The Christie NHS Foundation Trust
Rhetoric and not Reality
So if we get it right … what’s the gain?
Patients who get the care they want ... when they want it ... in the place they want it ... with the right people around them ... with the most gain
The impact of advance care planning on end of life care in elderly patients: randomised controlled trial

Karen M Detering, respiratory physician and clinical leader,1 Andrew D Hancock, project officer,1 Michael C Reade, physician,2 William Silvester, intensive care physician and director1

ABSTRACT

Objective To investigate the impact of advance care planning on end of life care in elderly patients.

Design Prospective randomised controlled trial.

Setting Single centre study in a university hospital in Melbourne, Australia.

Participants 309 legally competent medical inpatients aged 80 or more and followed for six months or until death.

decisions,1,2 resulting in patients being cared for in a way they would not have chosen.2 This has continued to the present day.4 Apart from progress in palliative care, the main focus to deal with these needs has been the development of advance care planning. Advance care planning is a process “whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care, should he or she become incapable
• 56 died by six months
• end of life wishes more likely to be known and followed (86% vs 30%)
• family members had significantly less
  • stress
  • anxiety
  • depression
• family satisfaction was higher in the intervention group (83% were very satisfied vs 48% in control)
• Patient satisfaction with acute stay was quiet different in the intervention group.

BMJ 2010
Box 1: Patients’ responses on discharge questionnaire

Intervention group

Outstanding staff
Very caring staff, no-one has asked me before what I would want when I get really sick. It was really great. It made me feel relieved
Everyone should have an opportunity to discuss these things
They asked me what I wanted and I told them and they listened... wow they really cared
They were so interested in what I thought

Control group

It was very hard to get information on what was happening
The doctors didn’t really listen
They all kept talking about me, but didn’t let me have a say. It was like I wasn’t important
They made me think that I was too old, and a nuisance and in the way
They didn’t speak to me and kept discussing everything with my family. I think they thought I was too old and couldn’t understand