Improving the experience of cancer care: exploring challenges of patient communication and strategies to improve health professionals' communication skills

Challenges when practicing shared decision-making in cancer care

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103M-T3

Track 3 – improving patient and family experiences

No conflicts of interest
The ancient doctor
The modern doctor

Paternalism or autonomy

Guidelines or judgement

Rights, needs or demands

Alternatives

Preferences

Patient or customer

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Shared decision-making (SDM)

• Advocated since the 1980s, mainly based on the ethical argument of respect for autonomy

• Makoul & Clayman (Patient Educ Couns 2006)
  • 31 separate concepts used to explicate SDM in 161 articles
  • Only patient values/preferences and options appeared in more than half of the definitions

• Stiggelbout et al (BMJ 2012)
  • Still far from implemented in medical care

• Gulbrandsen et al (Patient Educ Couns 2014)
  • A lot of confusion in and about SDM
When do SDM?

If equipoise?

...whatever that is...
A challenging movement alliance

The 5 Steps of Evidence-Based Medicine

1. Ask a clinical question
2. Acquire the best evidence
3. Appraise the evidence
4. Apply the evidence
5. Assess your performance

What is shared decision making?

Doctors share information
Patients consider options
Together they make a decision
Challenges related to complex information

Generally acknowledged information deficit
«I told them, they always forget»

The ”informed patients” myth
«...entering my room with a pile of printouts»

People’s limited numeracy and health literacy
«...even doctors don’t understand statistics...»
Shared decision-making has largely become a question of sharing information...

...based on the assumption that if patients were just given enough relevant information, they would want and manage to make decisions
But what is cancer care about?

An existential threat
creating awareness of **uncertainty**
evoking **vulnerability**
compromising **autonomy**
eliciting a need to **trust**
What happens to information?

*CanCORS study: 1193 patients, alive at 4 months after diagnosis, receiving chemo for newly diagnosed metastatic lung or colorectal cancer*

69% with lung cancer and 81% with colorectal cancer did not understand that the treatment was not curative.

The patients that mistakenly were thinking that the treatment was curative were almost twice as likely to rate their communication with their physician as favorable.

*Weeks et al, NEJM 2012*
UNCERTAINTY

Epistemic (empirical, probabilistic)
Aleatory (random)
How is uncertainty conveyed?

Audiotapes of 197 consultations between 27 oncologists and patients with early stage breast cancer with post-visit interviews

Uncertainty disclosed in 47% of consultations

- 23 allusions to epistemic uncertainty
- 84 allusions to aleatory uncertainty
- Patients contradicted themselves when speaking about epistemic uncertainty

- Aleatory uncertainty is the type of uncertainty most patients perceive and seem comfortable discussing

Intermediate conclusion

If SDM in cancer care is reduced to a question of information transfer alone, it will fail.
So...what more is SDM about?

Autonomy
Power
Trust
(Bilateral) vulnerability
Agency
Responsibility
Symptoms

Perceived uncertainty

Vulnerability

Dependency on the power of others

Autonomy

Healthy

Autonomy as a status

Autonomy as a capacity

Time
2nd axiom of human communication

You never communicate just a message. You always also communicate a relation.

A look at trust: An existential need

Grimen H. Med Anthropol Q 2009
Symptoms

Perceived uncertainty

Vulnerability

Dependency on the power of others

Time

Autonomous capacity

Healthy

Low

Seeking a physician

Goal of SDM

Potential range of autonomous capacity

Power

Trust

Scientific uncertainty

Vulnerability

Agency

Responsibility

Gulbrandsen et al, Patient Educ Couns 2016
Whose decision?
Shared decision-making recipe

Elwyn G et al, Patient Educ Couns 2013
SDM is a revolution in healthcare.

It is highly complex and partly conflicting with inherent characteristics of the doctor-patient relationship.

It is even more challenging when much is at stake.

There is no consensus about when to apply SDM.

SDM requires a lot of supervised training.

It has to be done. Good luck!
We should not primarily do SDM in order to respect patient autonomy, but in order to restore the patient’s autonomy.
The modern encounter

Thank you!