

Addressing Hope and Expectations

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Getting started...

- Why did you come to this workshop?
- What do you 'hope/expect'?

Consider...

- Jared is 16 years old and in the hospital again due to complications from his cystic fibrosis. The last few years have already been rough with a number of admissions, and things are not looking very good at the moment. Jared has said that he is reluctant to continue with his treatments and wants to start thinking about making the most of the time he has left.

■ Jared's parents are pushing for more "aggressive care" and don't know what to do about Jared's recent statements.

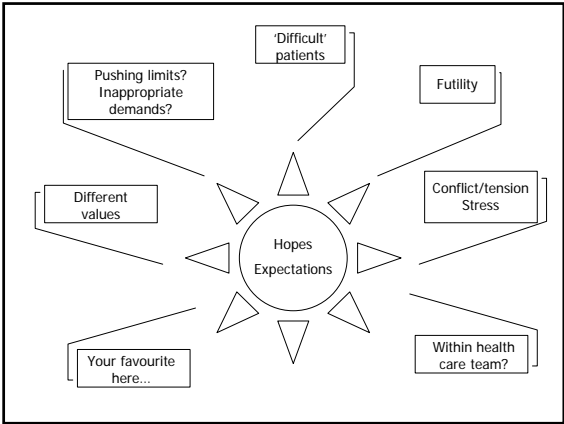
■ The health care team is uncertain about what would be "best" for Jared and disagree about how to approach both Jared and his parents.

(Roll-out for IWK Ethics Tool)

Thinking about language...

■ What are some of the ways we might describe or refer to a case like Jared's?

- Where do our words and descriptions take us?



Thinking about language...

- Is hope distinct from expectation?
- How would you define/describe these terms?

Thinking about language...

- Hope and expectation
 - Often talked about similarly in health care
 - Realistic, unrealistic, met, unmet
 - Question of whether need to respond to and/or need to share the same
 - Is a sense of obligation attached?
 - Connection between hope/expectation and experience?

Significance of...

- Impact on care
 - For specific patient, across patients, and patient groups
- Impact on relationships
- "Take-away" effects and affective aspects

An estimated 10% to 60% of patients treated in health-care settings exhibit "difficult behavior."

(Wasan, Wootton, Jamison, 2005)

Why we may want to...

- Identify and reflect on relevant values, assumptions, points of difficulty, etc.
- Consider personal, professional and organizational responses

Consider...

- Birdie has end stage renal disease and will likely need dialysis within the next six months. She has said that she wants to go on dialysis when it's time and may consider being put on the transplant wait list

■ The social worker, Chad, and her physician, Ashra, have been talking with Birdie about these changes in her health. They are frustrated that Birdie doesn't seem to understand that her situation is serious and that she should start thinking about the future. Instead, Birdie seems focused primarily on her daily counts and what she's eating.

With your table...

■ What do you believe is going on in this case?

■ What are some hopes/expectations that Birdie, Chad, and Ashra may have?

■ What might be some of the relevant (personal, professional, organizational) values at play?

What about the broader context?

■ Various influences and pressures on health care and how we understand different treatment options

- What are some examples?
- How might these shape our (everyone's) hopes and expectations?

Consider...

Revisiting the biomedicalization of aging
(Kaufman, Shim, Russ, 2004)

- New ethical field, located in the social fabric and characterized by the difficulty or impossibility of saying “no” to life-extending interventions...

Three features:

- Ways in which routine medical care overshadows choice
- Transformation of the technological imperative to a moral imperative
- Coupling of hope with the normalization and routinization of life-extending interventions

Some further questions...

- Are unrealistic or inaccurate hopes and expectations a problem of the patient or the HCP or both?
- Is there a link to increased involvement in decision-making and shared decision-making?
 - E.g., we encourage it, but do we really support it?

Some further questions...

- What is the role and place of substitute decision-makers and family members?
 - Do family members have unique needs?
What about their hopes/expectations?

Ways forward?

- When everyone is not 'on the same page', it can be helpful to (see Back, Arnold, 2005):
 - Notice – the situation, your feelings, etc.
 - Prepare – am I ready for the conversation?
 - Examine – what is happening, how this involves my identity
 - Find – appropriate start for conversation
 - Reframe – possible to move away from me against you?
 - Look – for options, negotiate (time trials?)
 - Ask – for help, other resources, as needed

Ways forward?

- Consider what is at stake with different hopes and expectations...
 - While don't need to share specific hopes or meet all expectations, what these mean or represent for people should not be overlooked
 - Relevance of vulnerability and power

Ways forward?

- Organizationally
 - Develop, review, and/or revise key policies
 - E.g., decision-making about potentially life-sustaining treatment
 - Education and sharing with internal and external communities
 - Consider “what is possible” and “what to expect” as starting points...
 - Other?