ACHD Symposium 2017

THE QUEENSTOWN MEETING

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Heart Failure/Late Problems:

End of Life Care: Psychology

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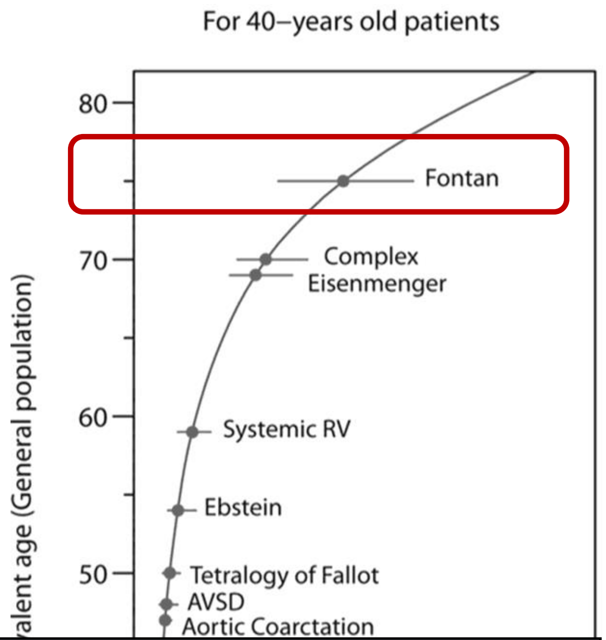
Standardized mortality ratio (SMR) analysis

Projected 5-year mortality rates for 40-year-old adults with CHD compared with



Many of our complex patients can be considered "geriatric" decades younger than their peers:

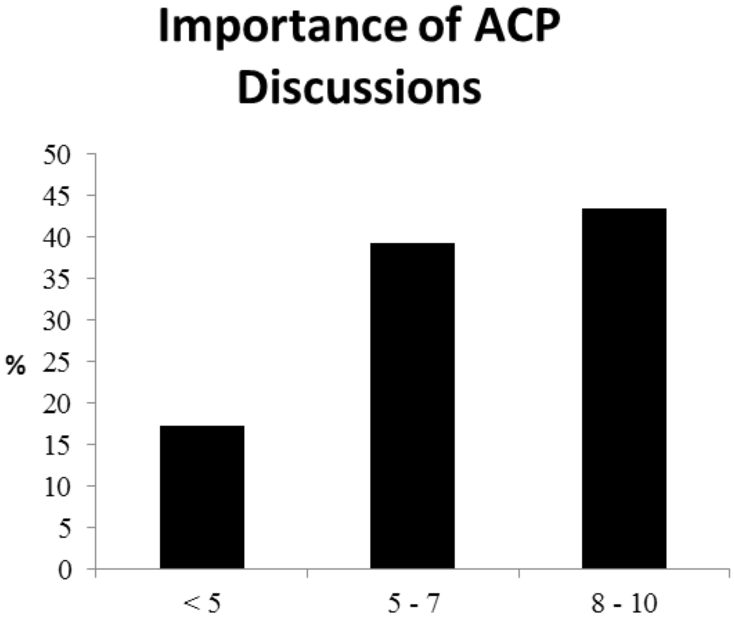
How do we psychologically prepare and support them with this?

Diller et al, Circulation, 2015

This is important to patients

Survey of 152 CHD outpatients (median age: 33) were asked:

On a scale of 0 to 10 (with 0 being least important and 10 being most important), how important is it to you to discuss advance care planning with your health care provider?



Note: median scores were **higher** (8 vs. 6) for patients with **clinically elevated symptoms of anxiety**

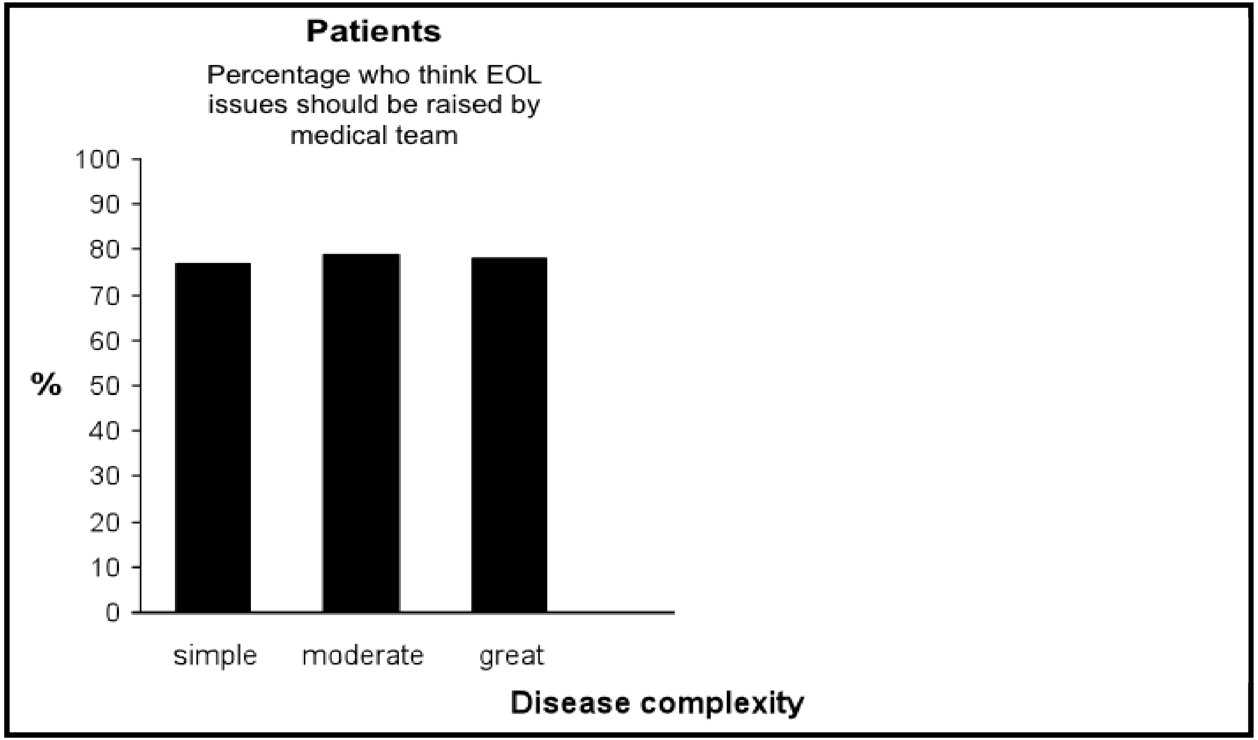
Deng et al, Int J Cardiol, 2017

This is important to patients

Survey of 200 CHD outpatients

- 35±15 years
- range: 18-79

Survey of 48 ACHD providers



Tobler et al, Int J Cardiol, 2012

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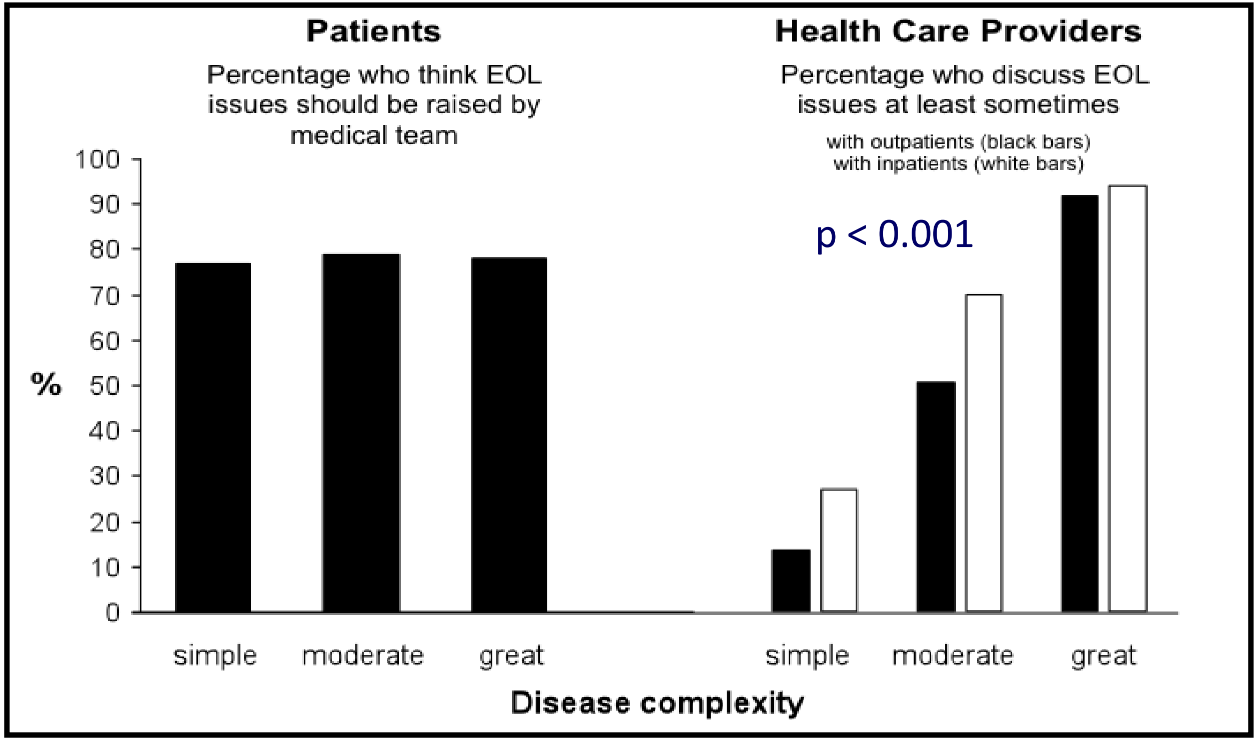
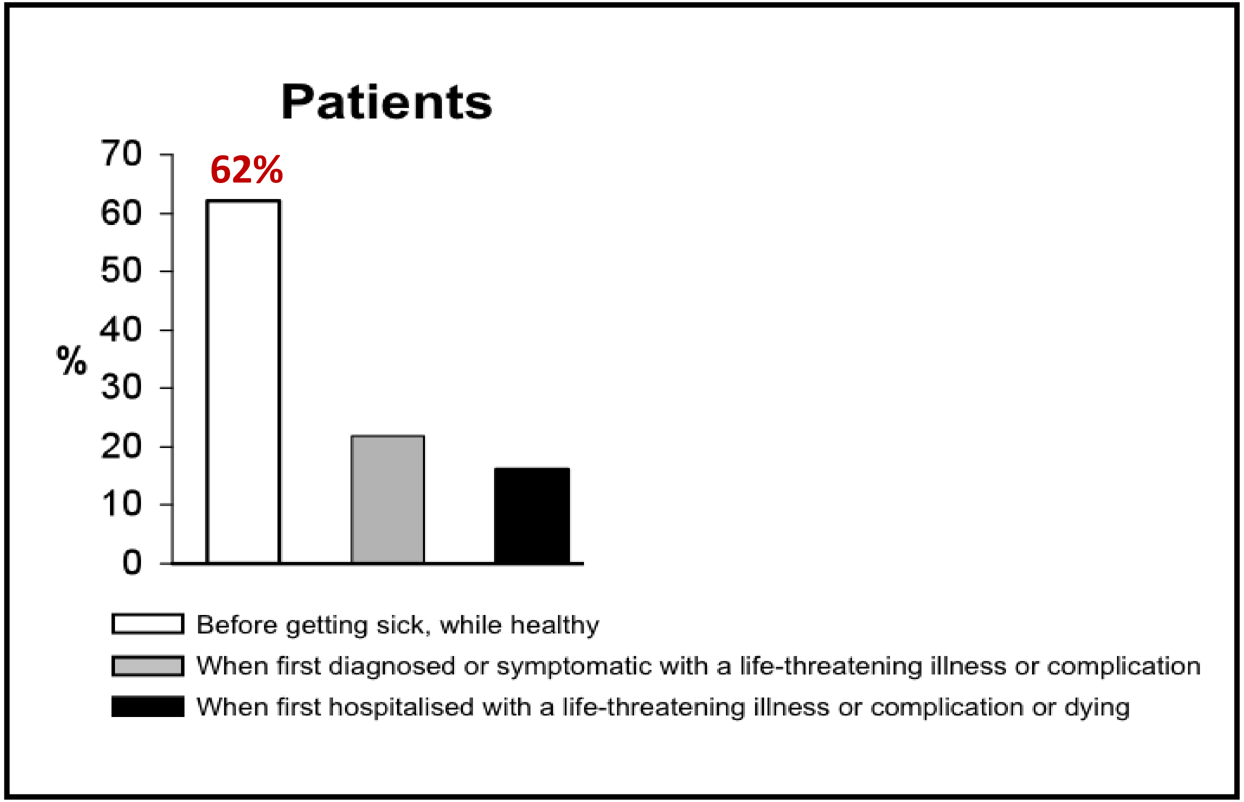


Tobler et al, Int J Cardiol, 2012

Starting in ‘advance’ of functional decline



Tobler et al, Int J Cardiol, 2012

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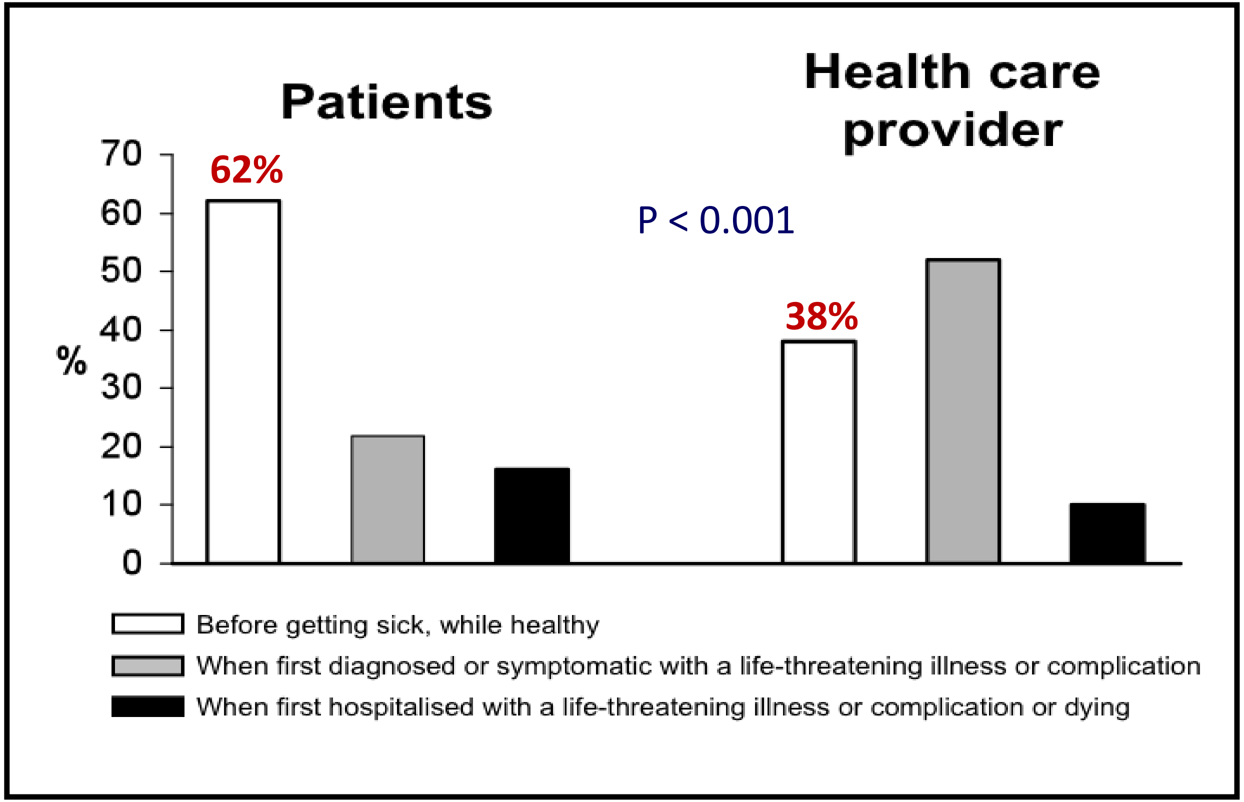

Tobler et al, Int J Cardiol, 2012

Advance care planning matters to patients

- Patient recalled previous end-of-life or advance care planning discussions with providers: 1 – 13%
- Patient reported completion of advance directives: 5 – 21%
- Patient has discussed end-of-life wishes with other people: 54 – 70%
- Patient would want information about the life expectancy of patients with their type of heart condition: 61 – 70%

Tobler et al, Int J Cardiol, 2012; Tobler et al, Am J Cardiol, 2012; Deng et al, Int J Cardiol, 2017

Optimism & realism are not mutually exclusive

- Seven Fontan patients aged 17-32
- Open-ended in-depth interviews
- Themes: happiness over being me, focusing on possibilities, **being committed to life**

> **"I don't know much about the future, I don't really think that I'll live until I'm very old . . .**
>
> **I don't think about it that often but when someone with a heart defect dies (someone I know) then I am kind of reminded about death, that it might be my turn next . . . We're sitting in the same boat, so to speak."**

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Berghammer et al, Congenit Heart Dis, 2015

Ways to support patients with advanced heart failure

- Normalize EOL discussions: explain that you hold them with all patients at this phase of their illness
- Schedule a specific visit and include family members as appropriate
- One size does not fit all: consider the cognitive and developmental ability as well as the cultural background of individual patients
- **Acknowledge the emotional impact** (for patients, families and providers)
- Document discussions and decisions
- Standardize your program’s approach to collaboration with palliative care and mental health professionals

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Kovacs, Landzberg & Goodlin, World J Ped Congenit Heart Surg 2012

Hoping for the best and preparing for the worst

- Provide a general range (days, weeks, months, years)
- Acknowledge prognostic uncertainty
- Consider the term “life-shortening medical condition”
- Be aware that some patients will under-estimate life expectancy whereas others will over-estimate
- Be mindful of patients’ experiences of having previously “beat the odds”
- **Recognize that the balance between being optimistic and realistic can be challenging (for patients, families and providers)**

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Kovacs, Landzberg & Goodlin, World J Ped Congenit Heart Surg 2012

Practice routine statements

“Many of our patients have questions about ‘what happens next’ as they start to experience a decline in their health. Many patients will wonder how long we think they might live and what the next phase of their health care might be like. We think it’s important to discuss these as well. Let’s plan a special visit to talk about these things. ”

“These might not be easy things to talk about but it is very important that we are on the same page. We need to talk about your preferences for end-of-life care and who you want to make decisions about your health if you become unable to do so. We think it’s really important to talk about these things in advance.”

The Ask-Tell-Ask Cycle

ASK what the patient currently understands about their health expectations and what they would like to know	"Given your worsening symptoms, what do you think the next phase of your health might be like?"
TELL information that is requested by the patient **or is important for them to know**	"We are at a turning point in your heart disease and there are choices about which road to take."
ASK again to confirm an understanding of what was said and to provide an opportunity for follow up questions	"It is important that I explain things clearly to you. Please tell me what you understood."

Kovacs, Landzberg & Goodlin, World J Ped Congenit Heart Surg 2012

Conclusion

Improving outcomes for patients with complex congenital heart disease entails:

Reducing morbidity and mortality

Optimizing quality of life and psychosocial outcomes

Providing the highest quality advance care planning & end-of-life experiences for patients and families

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