



**2013 International Shared Decision Making Conference**

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## 21. ▲ Decisional Needs in Patients Considering Left Ventricular Assist Device as Destination Therapy:

### Contrast between Acceptors and Decliners

Colleen McIvnenman, Larry Allen, Carolyn Nowel, Andreas Brieke, Daniel Matlock

University of Colorado

#### BACKGROUND

Left ventricular assist device as destination therapy (DT LVAD) is an option for some transplant ineligible patients who are actively dying of heart failure. Essentially, patients are faced with the decision to undergo major surgery to implant a partial artificial heart or transition to end-of-life care. While LVADs can extend life, they are also associated with significant risks including infection, stroke, and caregiver burden. How patients make this decision is poorly understood.

#### METHODS

We performed semi-structured, in-depth interviews based on the Ottawa Decision Support Framework to understand patients' decisional needs in accepting or declining DT LVAD. All patients who had DT LVAD in place and patients who declined DT LVAD at an academic medical center between October-December 2012 were interviewed. Interviews were audio-recorded and transcribed. Data were analyzed using a mixed inductive and deductive approach. Additionally, we measured their decision regret.

#### RESULTS

- All 17 eligible patients were interviewed, 13 with DT LVADs and 4 who had declined. Their mean age was 68.
- Patients accepting DT LVADs often did not perceive a decision. "I had to do it if I wanted to exist anymore." This perception appeared to come from a belief that choosing end-of-life medical care was not an option, "This [LVAD] was the only option I had...that or push up daisies...so I automatically took this." They also noted that the risks of the LVAD were not that important as they had "nothing to lose."
- Those who declined an LVAD stated they were not afraid of death, asserted that their life lived had meaning, and recognized the potential burdens to both themselves and their family, "There are worse things than death."
- For both accepters and decliners, this was an emotionally and spiritually driven decision. Both groups felt highly involved and informed and endorsed little decision regret (mean 5/100 for acceptors, 0/100 for decliners).

#### CONCLUSIONS

There is a fundamental difference in values surrounding death among patients who either accept or decline a DT LVAD. Decision support interventions around this complex medical decision need to consider patient values first before getting into more cognitive aspects of the decision making process.

## 11. ▲ Development and Evaluation of a Shared Decision Making Training Workshop for Health Care Professionals in Primary Care in Malaysia.

Khatijah Lim Abdullah <sup>a</sup>, Yew Kong Lee <sup>a</sup>, Ping Yain Lee <sup>b</sup>, Ee Ming Khoo <sup>a</sup>, Wah Yun Low <sup>a</sup>, Wei Seng Chen <sup>c</sup>, Abdul Samad Azah <sup>d</sup>, Akmal Syahidatul <sup>a</sup>, Chirk Jenn Ng <sup>a</sup>

<sup>a</sup> University of Malaya

<sup>b</sup> University Putra Malaysia

<sup>c</sup> Klinik Alam Medic

<sup>d</sup> Klinik Kesihatan Pantai

#### BACKGROUND

Shared Decision Making (SDM) and the use of patient decision aids (PDA) have increasingly been promoted in various healthcare settings. Health care professionals (HCP) training is important in the implementation of SDM in clinical practice. This paper describes the development and evaluation of a SDM training programme for HCPs in primary care.

#### METHODS

A multidisciplinary expert panel, comprising primary care doctors, nurse educators, psychologists and SDM expert, met over two days to develop a HCP training programme. These involved three steps: (1) reviewing literature on SDM training and clinical evidence, (2) expert consensus and (3) pilot study. A training workshop and a pocket sized HCP guide were developed. The training workshop includes short lectures, a show and tell demonstration of the PDA, video presentation and role-play. The HCP guide contains seven sections: introduction, contents, the how and when, HCP role, the evidence table and frequently asked questions.

Subsequently, three training workshops were conducted at three health clinics using the PDA guide. Each training workshop lasted 1 ½ hour and active participations were encouraged using role play based on case scenarios. At the end of the workshop the participants completed a questionnaire on their views of the workshop, the HCP guide and the PDA using a 5-point Likert scale.

#### RESULTS

A total of 41 HCPs participated. About half of them were medical doctors (n=22) while the rest were allied health care professionals. The proportion of the participants who rated the training programme as 'good' was as follows: 61 % (n=25) for explanation on SDM concepts, 66 % (n=27) for show and tell sessions, 59% (n=24) for PDA scenarios, 64 % (n=26) for participants' participation. Seventy six percent (n=31) and 63% (n=26) of the participants found the duration of the workshop and the amount of information just right respectively with 73% (n=30) expressed confidence in using the PDA.

#### CONCLUSION

The HCP guide and workshop were acceptable and feasible for training HCPs to use the PDA. Further studies are needed to assess the use and impact of the PDA in the clinical setting.