



How confident is your 'substitute decision-maker' that they can step in and make life and death decisions on your behalf?

BACKGROUND

With a serious illness or the end of a person's life, there can be very complicated decisions to make about medical treatment. Many seriously ill older adults will experience a time when they cannot make their own medical decisions — shifting that responsibility to their substitute decision-maker (SDM).

However, it can be very hard to make important medical decisions on behalf of a loved one. People in this position often have difficulty choosing care plans that are consistent with their loved one's wishes. SDMs typically experience significant stress, anxiety and long-term psychological consequences if unprepared for this role.

Advance Serious Illness Planning is a process that helps people share their personal values, life goals and preferences for medical care with the people who may need to make medical decisions for them.

Many people have made end-of-life arrangements such as a will or funeral plans, but they have not done Advance Serious Illness Planning to prepare their SDM.

45 PARTICIPANT DYADS
Patient 65 years or older and their substitute decision-maker

9 PRACTICE SETTINGS
Family practice, cardiology, cancer pain and symptom management, and chronic obstructive pulmonary disease clinics in Ontario

RATIONALE

The Plan Well Guide™ is a tool that can help people engage in advance serious illness planning, which enables them to share their values, goals and wishes — reducing their loved ones' stress and anxiety when they are called upon to make decisions about medical care.

THE PLAN WELL GUIDE

Plan Well Guide™ can help you

1. understand the difference between serious illness and terminal care, and the significance of making decision when you're uncertain,
2. define personal values, why these are important in decision-making and how trade-offs are sometimes required,
3. learn about different approaches to care in hospital and the outcomes of various treatment options (resuscitative/intensive care, medical care, comfort care) with visual aids and
4. be guided through a process to link personal values to preferences

OUR STUDY

- Study ran September 2017 to October 2019
- Participants (n=66 patient and SDM dyads) were randomized to receive the intervention immediately or in three months
- A research nurse ran the interactive Plan Well Guide™ (slides with voiceover) for the patient and SDM and completed the structured paper-based values clarification and preference questions with the patient when prompted by the decision
- The outcome was a survey of the SDM's readiness and confidence* for their role, measured three months later
- The study was limited by recruitment challenges
 - patients believe they had planned for end of life and that their SDM would know their wishes
 - it was difficult to recruit SDMs sometimes even when the patient was interested
- The trial was stopped early because of difficulties with enrolling and following up the planned sample of 90 patient and SDM dyads

RESULTS

- The mean change on the SDM survey favoured the Plan Well Guide group, but the difference was not statistically significant (mean difference =0.2 (95% CI: -0.3 to 0.6, p=0.39)
- In a post-hoc subgroup analysis, there was a significant difference in favour of the Plan Well Guide group in participants with a lower-than-median baseline score compared with those at or above the median (mean difference=0.6, 95% CI: 0.03 to 1.2, p=0.04).

CONCLUSIONS

In this statistically underpowered trial the Plan Well Guide™ did not increase the preparedness of SDMs for their role.

However, use of the Plan Well Guide™ led to a significant improvement among SDM who were the least prepared at the start.

Howard M, Elston D, Borhan S, Hafid A, Arora N, Forbes R, Bernard C, Heyland DK. (2021) A randomized trial of a serious illness decision aid (Plan Well Guide) for patients and their substitute decision-makers to improve engagement in advance care planning. *BMJ Supportive & Palliative Care*. Published Online First: 30 June 2021. doi: 10.1136/bmjspcare-2021-003040.

* The SDM survey measures knowledge, contemplation and readiness to act as an SDM (Van Scoy LJ et al. Adaptation and Preliminary Validation of the Advance Care Planning Engagement Survey for Surrogate Decision Makers. *Journal of Pain and Symptom Management* 2019;57:P980-988.e9.)

Get proactive, get prepared, get a plan!

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