Patient Education and Counseling xxx (2018) xxx–xxx

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou

Effects of advance care planning on confidence in surrogates' ability to make healthcare decisions consistent with older adults' wishes: Findings from a randomized controlled trial

Gina Bravo[a,b,*], Modou Sene[b,*], Marcel Arcand[b,c], Élodie Hérault[b]

[a] Department of Community Health Sciences, Faculty of Medicine and Health Sciences, University of Sherbrooke, Sherbrooke, QC, Canada
[b] Research Centre on Aging, University Institute of Geriatrics of Sherbrooke, Sherbrooke, QC, Canada
[c] Department of Family Medicine, Faculty of Medicine and Health Sciences, University of Sherbrooke, Sherbrooke, QC, Canada

ARTICLE INFO

Article history:
Received 12 August 2017
Received in revised form 8 January 2018
Accepted 7 February 2018

Keywords:
Substitute decision making
Health care
Advance care planning
Confidence
Older adult
Decisional incapacity

ABSTRACT

Objective: To investigate how confidence in surrogates' ability to make consistent decisions in the future change over time, in the context of an ACP intervention that did not improve surrogates' ability to predict an older adult's hypothetical treatment preferences.
Methods: The study involved 235 older adults and surrogates, randomly allocated to an ACP or control intervention. At baseline, end of intervention, and six months later, participants were asked how confident they were in the surrogate making decisions in the future that would match the older adult's wishes.
Results: By the end of the intervention, confidence had increased among older adults and surrogates involved in ACP (OR = 3.1 and 5.8 respectively, $p < 0.001$), while less change occurred among controls. Over the following six months, confidence remained stable among older adults but decreased among surrogates (OR = 0.5, $p = 0.005$).
Conclusion: ACP increases confidence in surrogates' ability to make consistent decisions, which may lighten the burden of substitute decision making. Efforts to improve substitute decision-making must continue so that participants' confidence is not based on the mistaken assumption that surrogates can make consistent decisions.
Practice implications: Professionals involved in ACP should inform participants that confidence in the surrogate may increase in the absence of enhanced predictive ability.

1. Introduction

Substitute decision making is frequent for older adults nearing the end of life, due to so many being decisionally incapacitated [1,2]. In a systematic review published in 2011, Wendler and Rid estimated that one-third of surrogates who make substitute health-related decisions for a loved one experience a negative emotional burden that may last months, even years [3]. Several studies, mostly qualitative, suggest that knowing which treatment the patient would have preferred lightens the burden of substitute decision making [3]. Knowledge of treatment preferences gives surrogates confidence that they can make the right decision and allows them to focus on quality of life as a guide to decision making [4–7]. Advance care planning (ACP) aims at helping people provide such knowledge to close relatives, the treating physician and other healthcare providers likely to be involved in decision making, by communicating their goals of care, values and beliefs through discussions and, sometimes, a written advance directive.

Using hypothetical clinical vignettes, a few experimental studies have tested whether ACP and/or access to the content of a directive does indeed enhance surrogates' ability to predict a loved one's hypothetical choices regarding the care he or she would want to receive in the event of incapacity [8–14]. Of these studies, three also assessed how confident surrogates felt about their ability to predict their loved one's wishes accurately [9,12,14]. High levels of confidence were observed in all three studies, despite surrogates' low ability to accurately predict their loved one's wishes. For example, Ditto and colleagues [9] randomized 401 elderly outpatients and their surrogates to one of five conditions. In the control condition, surrogates predicted patients' preferences in various illness scenarios without reviewing the

* Corresponding author at: Research Centre on Aging, University Institute of Geriatrics of Sherbrooke, 1036 South Belvedere Street, Sherbrooke, QC, J1H 4C4, Canada.
E-mail address: Gina.Bravo@USherbrooke.ca (G. Bravo).

https://doi.org/10.1016/j.pec.2018.02.005
0738-3991/

patient's advance directive. Surrogates' predictive ability in this condition was compared with that in four intervention conditions in which surrogates made predictions after reviewing or discussing the content of the directive. None of the interventions produced significant improvements in surrogates' predictive ability. Yet most surrogates were confident in their ability to predict patients' treatment preferences. Patients were equally confident in surrogates' predictive abilities. Commenting on these findings, Fagerlin and Schneider [15] raised the concern that people are being deceived into thinking that engaging in ACP or filling out an advance directive will increase their surrogates' ability to make more consistent substitute decisions in the future.

We recently conducted a repeated-measures randomized controlled trial to assess the effects of a multimodal ACP intervention designed for community-dwelling older adults and their surrogates [16]. Trial outcomes included surrogates' ability to predict the older adults' preferences for health care should they become decisionally incapacitated. This outcome was measured using a series of clinical vignettes modeled on those developed in past research [16]. For instance, older adults were asked whether they would want to receive antibiotics intravenously to treat a life-threatening infection, or to undergo cardiopulmonary resuscitation in case of cardiac arrest, assuming they suffered from severe dementia. Questions were asked in three occasions, i.e., at baseline and twice after the intervention. Parallel questions were asked to the surrogates to determine whether their ability to predict the older adults' answers improved over time.

As detailed in a paper published in an earlier issue of this *Journal* [17], the advance planning intervention failed to improve the surrogates' ability to make hypothetical healthcare decisions that match those of the older adults. As part of the data collection, older adults and surrogates were also asked how confident they were in the surrogate making health-related decisions in the future that would be consistent with the older adult's wishes. This paper reports findings from analyzing confidence levels, with the objective of determining how they evolved over time in the context of an ACP intervention that was not effective in increasing surrogate's predictive ability. To our knowledge, this study is the first to measure confidence levels at multiple points in time among community-based older adults and surrogates jointly engaged in advance planning. Complementing findings presented in our previous paper, those reported here could benefit healthcare professionals involved in delivering ACP interventions by enhancing their understanding of the possible effects of such activities.

2. Methods

The randomized controlled trial received prior ethical approval from the Research Ethics Board of the University Institute of Geriatrics of Sherbrooke. All participating older adults and surrogates provided written informed consent at trial entry.

2.1. Target population and study design

As described in more detail elsewhere [16,17], the target population was formed of dyads in which French-speaking, community-dwelling, decisionally competent adults aged 70 years or older were paired with the person they would choose to make healthcare decisions on their behalf should they lose the capacity to make decisions on their own (hereafter called the surrogate). In the Canadian province of Quebec where this study was conducted, 94% of the population speaks French [18]. Potentially eligible older adults were randomly sampled from the administrative database of the Quebec universal health insurance plan. They were mailed a personalized letter describing the study and called one week later to assess their eligibility and willingness to enroll. The call included administering a short memory test to screen out older adults who were likely unable to engage actively in ACP. Eligible older adults willing to enroll in the trial were randomized with their surrogate to the experimental or control group, after stratification for type of selected surrogate (spouse or other) and self-report by the older adult of prior documentation of healthcare wishes (yes or no).

2.2. Experimental and control interventions

Three monthly activities of approximatively two hours each were organized for each group. For the experimental group, these included: i) a first home visit by a specially trained social worker who helped older adults reflect on and communicate their personal values, beliefs and wishes regarding future health care to their surrogates; ii) a group information session on the purposes, uses, and practical limitations of recording healthcare wishes in an advance directive; and iii) a second home visit by the same social worker who checked participants' understanding of the information delivered during the group session, provided clarification as required, and assisted interested older adults in documenting their wishes. Meanwhile, control dyads attended three nurse-led interactive workshops promoting healthy behaviors. Topics covered included, for example, stress management, sleep habits, and physical activity. ACP was not discussed during these health-education workshops. Further information on the experimental and control interventions can be found in Bravo et al. [16,17].

2.3. Data collection

Data were gathered from all trial participants, by two specially trained research nurses, at three points in time: at baseline, at the end of the three-month interventions, and six months later. In all instances, the in-person interviews with the older adult and surrogate were conducted simultaneously in separate rooms of the Research Center so as to be blind to their partner's answers. The baseline interview began by asking participants to sign the consent form and answer a series of questions about themselves. Questions included how confident they were that future health-related decisions made by the surrogate on behalf of the older adult would match the latter's wishes. This question was repeated at the end of the interventions, and again six months later. Answers were provided on a 4-point Likert scale ranging from *not confident at all* to *totally confident*.

2.4. Statistical analyses

Owing to small cell frequencies, the first and second response categories (*not confident at all* and *not very confident*) were combined for analysis. We used the generalized estimating equation (GEE) approach for clustered ordinal outcomes [19,20] to investigate the effect of the experimental intervention on confidence levels over time, among both older adults and surrogates. Results are reported using odds ratios (ORs) and associated 95% confidence intervals. Analyses were performed with SAS Proc GENMOD, version 9.4 (SAS Institute Inc., Cary, NC), using a cumulative logit link function for multinomial data and an independence working correlation structure for the responses [19].

3. Results

3.1. Selected characteristics of trial participants

As previously reported [17], 2451 older adults were randomly sampled, of which 575 could not be reached, 315 were judged

Please cite this article in press as: G. Bravo, et al., Effects of advance care planning on confidence in surrogates' ability to make healthcare decisions consistent with older adults' wishes: Findings from a randomized controlled trial, Patient Educ Couns (2018), https://doi.org/10.1016/j.pec.2018.02.005