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An advance directive redesigned to meet the literacy level of most adults: A randomized trial☆,☆☆

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Abstract

Objective: To determine whether an advance directive redesigned to meet most adults' literacy needs (fifth grade reading level with graphics) was more useful for advance care planning than a standard form (>12th grade level).
Methods: We enrolled 205 English and Spanish-speaking patients, aged ≥50 years from an urban, general medicine clinic. We randomized participants to review either form. Main outcomes included acceptability and usefulness in advance care planning. Participants then reviewed the alternate form; we assessed form preference and six-month completion rates.
Results: Forty percent of enrolled participants had limited literacy. Compared to the standard form, the redesigned form was rated higher for acceptability and usefulness in care planning, $P \leq 0.03$, particularly for limited literacy participants (P for interaction ≤0.07). The redesigned form was preferred by 73% of participants. More participants randomized to the redesigned form completed an advance directive at six months (19% vs. 8%, $P = 0.03$); of these, 95% completed the redesigned form.
Conclusions: The redesigned advance directive was rated more acceptable and useful for advance care planning and was preferred over a standard form. It also resulted in higher six-month completion rates.
Practice implications: An advance directive redesigned to meet most adults' literacy needs may better enable patients to engage in advance care planning.

Keywords: Advance directive; Health literacy; Communication; Decision-making; Ethics; Health disparities

1. Introduction

Written advance directives have been advocated to document end-of-life treatment wishes, designate surrogate decision makers, and promote discussion regarding treatment wishes [1]. While advance directives are not a panacea for the challenges of advance care planning, and there is controversy concerning their effectiveness [2–4], they are desired by patients [1,5] and may stimulate discussions and decrease stress for surrogate decision-makers [6,7]. In many countries, healthcare organizations are required to provide information about advance directives to patients [8].

Advance directive completion rates are low, especially among more disadvantaged populations [9]. Standard advance directives may themselves be a barrier to completion and understanding because most forms are written at a 12th grade reading level and contain complex medical and legal terminology [10]. In contrast, half of American adults read at or below an eighth grade level (fifth grade or a mid-primary educational level for the elderly) [11] and an estimated 20% of European adults have literacy skills that would prevent them from "learning from text" [12].

Limited literacy has been associated with impaired information exchange, decision-making, and communication

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of treatment preferences [13]. The combination of limited literacy and poor advance directive design results in a mismatch that may jeopardize decision-making around end-of-life care. The Institute of Medicine and other organizations have called on the healthcare system to improve access to information to enable patients to actively participate in decision-making. Specific recommendations include writing medical documents at a sixth-to-eighth grade reading level and designing written documents with an easy-to-follow format and layout [14].

Methods used to design literacy-appropriate written materials include not only writing the text at a lower reading level, but also designing the materials with an appropriate layout that enhances readability. Therefore, we redesigned a standard advance directive to meet the literacy levels of most elderly adults by writing the text at a fifth grade reading level, i.e. mid-primary educational level. We also incorporated input from the target population [15] and used a clear layout, large 14-point font, appropriate line spacing and margins, and graphics that helped to explain the text [14,16–19]. These techniques have been shown to improve acceptability [16,17], activate patients to initiate discussions with providers [17] and, in some cases, enhance understanding [16,18,19]. We then conducted a randomized trial to compare the redesigned to a standard form (Fig. 1). To our knowledge, no prior studies have assessed an advance directive redesigned in this manner. We hypothesized that participants would rate the redesigned advance directive easier to use and understand, more useful for personal treatment decisions, and more valuable for care planning. Because the hospital in which the redesigned advance directive was to be implemented has a large proportion of Spanish-speaking patients and patients with limited literacy [20,21], and because engagement in advance care planning has

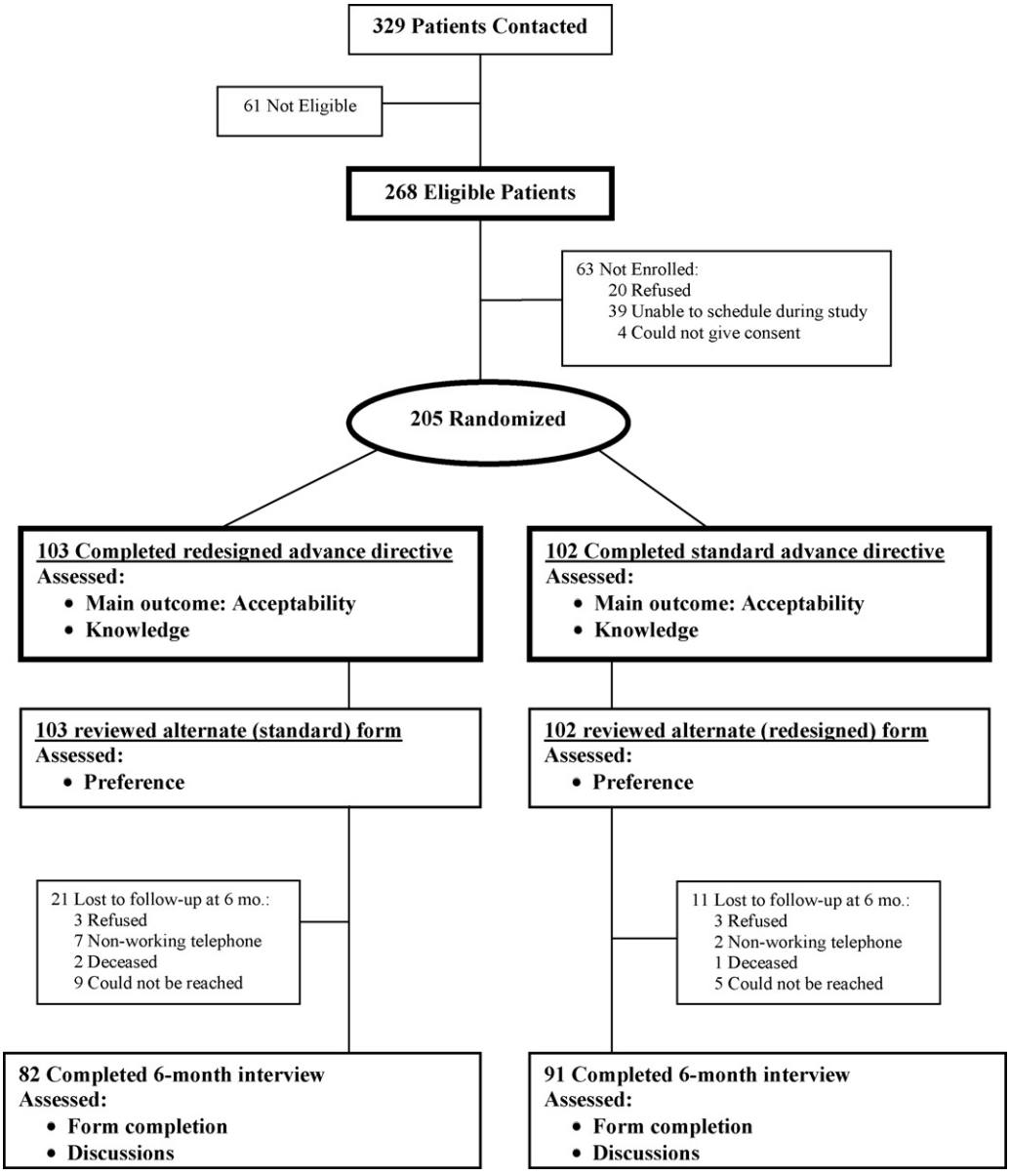

Fig. 1. Participant flow diagram.