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Digital Advance Care Planning and Directives: Early Observations of Adoption Statistics and Responses from an All-Digital Consumer-Driven Approach

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Abstract: Importance: Barriers to traditional advance care planning (ACP) and advance directive (AD) creation have limited the promise of ACP/AD for individuals and families, the healthcare team, and society. Reengineering ACP by using a web-based, consumer-driven process has recently been suggested. We report early experience with such a process. Objective: Begin to analyze the potential of the creation and use of ACP/ADs as generated by a consumer-friendly, digital process by 1) assessing the likelihood that consumers would create ACP/ADs without structured intervention by medical or legal professionals, and 2) analyzing the responses to determine if the plans can help doctors better understand a person's goals, preferences, and priorities for their medical treatments and the naming of healthcare agents. Design: The authors chose 900 users of MyDirectives.com, a digital ACP/AD tool, solely based on their state of residence in order to achieve proportional representation of all 50 states by population size and then reviewed their responses, summarizing these through descriptive statistics including treatment preferences, demographics, and revision of preferences. Setting: General United States population. Participants: The 900 participants had an average age of 50.8 years (SD = 16.6); 84.3% of the men and 91% of the women were in self-reported good health when signing their ADs. Main measures: Preferences regarding the use of lifesustaining treatments, where to spend final days, consulting a supportive and palliative care team, attempted cardiopulmonary resuscitation (CPR), autopsy, and organ and tissue donation. Results: Nearly 85% of respondents prefer cessation of lifesustaining treatments during their final days whenever those may be, 76% prefer to spend their final days at home or in a hospice facility, and 94% wanted their future doctors to consult a supportive and palliative care team. 70% would accept attempted CPR in certain limited circumstances. Most respondents would want an autopsy under certain conditions, and 62% would like to donate their organs. Conclusions and relevance: Analysis of early experience with an all-digital web-based ACP/AD platform demonstrates that individuals from a wide range of ages and conditions can engage in an interrogatory process about values, goals, preferences, and priorities for their medical treatments by developing advance directives and easily make changes to the AD created. Online creation, storage, and retrieval of advance directives has the potential to remove barriers to ACP/AD and, thus, to further improve patient-centered end-of-life care.

Keywords: Advance Care Plan, Advance Decisions, Advance Directives, Consumer; Digital, End of Life Care, Goals, Living Wills, Prefences, Universal Advance Directive, Statements

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