

2.2 ACP 2.0

O30

Scoping Review about Web-based Advance Care Planning Programs

D. van der Smissen¹, A. Overbeek¹, S. Van Dulmen², J. Van Gemert-Pijnen³, A. van der Heide¹, J. Rietjens¹, I. Korfage¹

¹Erasmus University Medical Center, Rotterdam, Netherlands

²NIVEL, Utrecht, Netherlands

³University of Twente, Enschede, Netherlands

Background: Advance Care Planning (ACP) enables persons to define goals and preferences for future medical treatments and care, to discuss, record and review these. Potentially, web-based programs can support patients in ACP. However, an overview of their effectiveness and feasibility is lacking.

Methods: To provide an overview of the content, feasibility and effectiveness of web-based, interactive and patient-centered ACP programs, we systematically searched in 7 databases. We extracted data using the EAPC consensus concept of ACP as our framework.

Results: The search identified 3434 records; 21 studies were included. Three additional studies were identified by hand search. The 24 studies evaluated 11 web-based ACP programs, developed in the USA (10) and Ireland (1). Most programs addressed exploration of goals, values and preferences, and ACP communication. Users considered programs as easy to use (7/7 studies) and not burdensome (7/8 studies). Users were satisfied with the programs (10/10 studies), ACP communication (11/11 studies) and ACP documentation (14/16 studies) increased. Two studies evaluated concordance between preferred and provided care. Designs of 10 studies allowed comparison before/after completing ACP programs or between study groups.

Conclusion(s): Most web-based ACP programs contain the important elements of ACP. Studies reported that programs tended to be effective and feasible. Evaluations of concordance between preferred and provided care are scarce. Web-based programs have potential to support patients, and scale up ACP. However, since many studies did not assess differences before/after or between groups, outcomes should be interpreted with caution.

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O31

Developing and improving a web-based tool for clients in long-term care: a user-centred design

C. van Leersu¹, A. Moser, B. van Steenkiste, E. Stoffers, M. Reinartz, J. Wolf, T. van der Weijden
Maastricht University, Maastricht, Netherlands

Background: The decision-making process for clients in need of long-term care is challenging and clients need to make choices about the care they prefer. A tool to assist the clients and caregivers with the decision-making and elicitation on preferences could be beneficial. The aim is to investigate user-requirements of a tool for the decision-making.

Methods: We applied a user-centred design to develop this tool. This was an interactive process of collecting data with end-users and improving the prototypes. The end-users included clients, relatives, and caregivers. Four end-users participated in a development team and 22 end-users were interviewed individually. We collected data during three phases of iteration: look and feel, navigation, and content. We analysed the data using thematic analysis and adjusted the prototype after each phase.

Results: The lay-out was approved by all participants during the look and feel phase, but there was a need for different/neutral pictures. During the navigation phase, participants experienced easy navigation, but text-blocks had to be shortened. Considering the content, participants missed questions about well-being/happiness. After the third phase, the tool was finalized.

Conclusion: The user-centred design was necessary to move from the prototypes to the finalized tool fitting usability-requirements of end-users. The tool 'What matters to me' (<http://www.watikbelangrijkvind.nl>) is currently in the feasibility-testing phase.

O32

Using Twitter to Explore Advance Care Planning Among Brain Tumor Stakeholders

H. Lum¹, N. Cutshall², L. Salmi, R. Berry, B. Kwan³

¹University of Colorado and VA GRECC, Aurora, United States of America

²University of Colorado, Aurora, United States of America

³University Of Colorado School Of Medicine, Aurora, United States of America

Background: Advance care planning (ACP) often occurs too late in the disease course of patients affected by brain tumors. Furthermore, the perspectives of brain tumor stakeholders on ACP are not well described. This study uses a social media tweet chat to understand perspectives on ACP among brain tumor stakeholders.

Methods: This qualitative descriptive study analyzed a tweet chat (real-time virtual group discussion on the social media platform Twitter) of brain tumor stakeholders. The 1-hour tweet chat was organized by the patient-run Twitter community referred to with the hashtag #BTSM, which stands for Brain Tumor Social Media. Participants reflected on four questions about ACP by including #BTSM in tweets. Unique tweets and stakeholder type (i.e. patient, caregiver, advocate or organization member, clinical provider and researcher, leader) were categorized. The tweet chat transcript was analyzed to identify key themes.

Results: Fifty-two participants from four countries contributed 336 unique Tweets. Most participants were patients, clinical providers or researchers, and advocates or organizations. There were four key themes regarding brain tumor stakeholder perspectives about ACP: 1) cultural barriers prevent discussions of death; 2) ensuring one's voice is heard; 3) Goldilocks' approach to timing – fearing ACP is too early or too late; and 4) crowdsourcing ACP resources.

Conclusions: A multi-national group of brain tumor stakeholders engaged in ACP discussions via a social media tweet chat and highlighted important challenges and opportunities. Social media is a new avenue in which clinicians and patients may engage with to better understand each other's perspectives related to ACP.

O33

Nationwide Multicenter Evaluation to Determine Whether Patient Video Testimonials Can Safely Help Ensure Appropriate Critical Versus End-of-Life Care

F. Mirarchi¹, M. Markley²

¹*Institute on Healthcare Directives, Erie, PA, United States of America*

²*M Jane Markley Consulting, LLC, Derwood, MD, United States of America*

Background: End-of-life interventions should be predicated on consensus understanding of patient wishes. Written documents are not always understood; adding a video testimonial/message (VM) might improve clarity. Study goals were to (1) determine baseline rates of consensus in assigning code status and resuscitation decisions in critically ill scenarios and (2) determine whether adding a VM increased consensus.

Methods: We randomly assigned 2 web-based survey links to 1366 faculty and resident physicians at institutions with graduate medical education programs in emergency medicine, family practice, and internal medicine. Each survey asked for code status interpretation of stand-alone Physician Orders for Life-Sustaining Treatment (POLST) and living will (LW) documents in 9 scenarios. Respondents assigned code status and resuscitation decisions to each scenario. For 1 of 2 surveys, a VM was included to help clarify patient wishes.

Results: Response rate was 54%, and most were male emergency physicians who lacked formal advanced planning, document interpretation training. Consensus was not achievable for stand-alone POLST or LW documents (68%–78% noted "DNR"). Two of 9 scenarios attained consensus for code status (97%–98% responses) and treatment decisions (96%–99%). Adding a VM significantly changed code status responses by 9% to 62% ($P \leq 0.026$) in 7 of 9 scenarios with 4 achieving consensus. Resuscitation responses changed by 7% to 57% ($P \leq 0.005$) with 4 of 9 achieving consensus with VMs.

Conclusions: For most scenarios, consensus was not attained for code status and resuscitation decisions with stand-alone LW and POLST documents. Adding VMs produced significant impacts toward achieving interpretive consensus.

O34

Finding What Matters: Using Natural Language Processing to Identify Patient Care Preferences within Clinical Notes

S. Zupanc¹, K. Lee², E. Moseley¹, I. Yeh¹, C. Lindvall¹

¹*Dana-Farber Cancer Institute, Boston, United States of America*

²*Brigham and Women's Hospital, Boston, United States of America*

Background: Delivering care that is consistent with patient preferences is considered the outcome of successful advance care planning interventions. However, patient preferences are often difficult to ascertain within clinical notes, and thus difficult to extract and utilize in clinical or evaluative settings. The objective of this study is to show the efficiency and accuracy of two natural language processing (NLP) methods in identifying documentation within the free-text of clinical notes.

Methods: Rule-based and machine learning NLP methods were developed and trained on a dataset of 449 clinical notes derived from Multi Parameter Intelligent Monitoring of Intensive Care (MIMIC) III database. Human annotators identified instances of code status limitation and patient care preference documentation in a second validation dataset of 192 clinical notes. We then assessed the performance of the rule-based and machine learning NLP methods in identifying code status limitation and patient care preference documentation in the validation dataset.

Results: Machine learning NLP identified documentation with a sensitivity ranging from 85.1-98.3% and a specificity ranging from 91.0%-97.0%. Performance of rule-based NLP was comparable, identifying documentation of code status limitation with a sensitivity of 98.3% and a specificity of 97.7% and patient care preferences with a sensitivity of 81.5% and a specificity of 83.0%.

Conclusions: NLP methods are reliable tools for identifying information related to patient care preferences within clinical notes. Machine learning NLP may be better suited to identify documentation of conversations that vary in the way they are recorded, such as conversations related to goals of care.