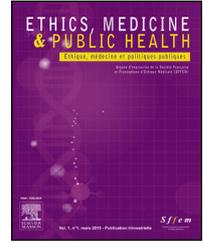




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METHODOLOGY

Blueprint for scaling advance care planning conversations to medical practices



Schéma de renforcement des conversations sur la planification préalable des soins dans les pratiques médicales

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Summary Establishment of the Community Conversations initiative in Schenectady County, New York began as a response to pleas from palliative care professionals who recognized the absence or paucity of Advance Directives (AD) in the medical records of referred patients. The palliative care physicians responsible for cases of the critically ill or those with diminished or no decisional capacity often faced the challenging task of locating a previously prepared AD, if any, identifying a healthcare proxy or agent who could speak on behalf of the patient (in terms of best interests or substituted judgment), or identifying clear and convincing evidence as to what, if any, life-sustaining treatment was expressed prior to illness. Practitioners and patients, both in the US and France, have historically avoided the confrontation and “the conversation.” Similarly, examination of shared decision making training programs evidenced wide variations in how and what they deliver. More importantly, evidence of their effectiveness was sparse. Studies on shared decision making programs suggest there is a need for international consensus on ways to address the variability in patient-centered programs concerning “the conversation” surrounding Advance Care Planning (ACP).

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MOTS CLÉS

Planification
préalable des soins ;
Engagement du
clinicien ;
Sensibilisation
communautaire ;
Méthode

Résumé L'initiative *Community Conversations* dans le comté de Schenectady à New-York fut initiée suite aux demandes des professionnels en soins palliatifs qui ont observé l'absence ou la rareté des directives médicales anticipées (DMA) dans les dossiers médicaux des patients référés. Les médecins en soins palliatifs qui sont en charge des personnes gravement malades ou ayant une capacité décisionnelle réduite ou absente, ont souvent la tâche difficile de trouver une DMA qui aurait été préparée précédemment, si elle existe, d'identifier un mandataire qui pourrait s'exprimer au nom du patient (dans son meilleur intérêt ou jugement substitutif) ou d'identifier des preuves claires et convaincantes des souhaits que le patient aurait exprimés avant la maladie. Les praticiens et les patients, autant aux États-Unis qu'en France, ont traditionnellement évité la confrontation et « la conversation ». De plus, une analyse des programmes de formation en prise de décisions partagées a montré qu'il y a une grande variance dans leurs contenus et ce qu'ils offrent. Qui plus est, il y a peu de preuves en ce qui concerne leur efficacité. Les études sur ces programmes soutiennent la nécessité d'un consensus international sur les façons d'aborder les différences qui existent entre les programmes axés sur les patients en ce qui a trait à « la conversation » entourant la planification préalable des soins (PPS).

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Introduction

Advance Care Planning (ACP) emphasizes a process of communication necessary to assist individuals in making informed decisions about their future medical care. The future is often difficult for people to embrace, especially when it concerns their medical care. When a person is healthy and robust, the thought of declining health and disabling illness is easily relegated to a place of insignificance, put out of sight or mind. Yet, this is precisely when the planning should be done. When a person has the capacity and presence of mind to make autonomous choices based on his own wishes and personal desires, he has the ability to make them known for the future. Those choices, which ideally should reflect the individual's values and goals, and which require significant personal consideration, can be made known in an Advance Directive (AD). An AD is a document that clearly represents an individual's preferences. It is a plan for future medical care regarding treatments or goals of care for a possible or probable event [1]. Furthermore, an AD prepares others to make healthcare decisions consistent with those preferences when a person no longer has the capacity to speak for himself [2]. It follows that when a person cannot speak for himself, he needs an advocate who can speak on his behalf—one who can offer substituted judgment, for example, when a medical decision or choice must be made for the person. This individual is typically known as a healthcare proxy. It is the healthcare proxy who consults with the medical staff and the patient's loved ones to arrive at a decision for goals of care and treatment. In an ideal situation, the healthy person has considered choices that reflect his wishes for a time when he might face declining health. He has also considered who his healthcare proxy should be and engaged in conversation with that person. If the healthcare proxy knows what the patient's values and goals were, the better equipped he is to help make decisions, even if an unanticipated scenario develops. Yet, this sequence of events is seldom manifested according to a recent report titled "Dying in America" released by the Institute of Medicine (IOM). The report indicates that "most

Americans have not documented their wishes for end-of-life care [3]." Often, a person falls ill before he has considered how he might like his plan of treatment to progress; he has not prepared an AD; he has not appointed a healthcare proxy. He has not held a conversation with this person, family, or physician. To clarify the elements necessary for the success of the Community Conversations project, this facilitator prepared a logic model (Table 1) to identify a pathway for reaching outcomes.

This article is made up of two distinct parts. Part 1 is background on the need for Advance Directives and evidence that the La Crosse model leads to Advance Directives and honoring patient choices. The Dartmouth Atlas evidence indicates that the La Crosse studies were effective in eliciting fewer hospital days and physician visits per capita [4]. Part 2 is the explanation of the Community Conversations project, outreach to clinicians, and the process involved in implementation.

Contextualization

A logic model – Identifying the path

Preparation of a logic model (Table 1) was instrumental in identifying and defining the objectives of the project. Activities were designated to be:

Comprehensive

A trained, certified facilitator would use tested, evidence-based training materials, and metrics. The output was an increased understanding of Advance Care Planning and increased motivation to begin having the conversation. Outcomes were measured using an evaluation tool.

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