

Characterizing Readiness for Advance Care Planning: An Interpretive Descriptive Study in Supportive Living

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BACKGROUND

Advance Care Planning (ACP) is a process that enables people to communicate wishes and preferences for future care. ACP helps ensure that the care patients receive aligns with their values, even if they become unable to express their treatment preferences (1).

ACP is especially relevant for people in supportive living (residential care) as they are often physically frail, at high risk of serious illness requiring treatment decisions and of cognitive decline, which may hinder their ability to consent to or refuse treatments. However, currently rates of ACP engagement are low (2).

Readiness to engage in ACP is feeling comfortable and willing to discuss issues related to disease prognosis, expectations and preferences for care. Readiness of patients, families and clinicians is necessary to engage in effective ACP (3). The factors associated with ACP readiness are not known for residents in supportive living.

The **purpose** of this study is to explore perceptions of readiness, as well as barriers and facilitators to ACP in supportive living residents, their families and clinicians.

METHODS

Larger Research Program

This study is part of a larger research program examining readiness for ACP in various clinical settings. We are using the same interview guides to examine perspectives of patients, their families and Healthcare Providers (HCP) in oncology, heart-failure and renal clinics. Here we report only the early findings from residents in Supportive Living.

Participants and data collection to date

Three participant groups were purposively recruited who represent the key individuals involved in ACP in a SL context: residents, family members (FM), and clinicians. Semi-structured one-on-one interviews were conducted with 27 participants:10 residents, eight FM and nine clinicians (including physicians, social workers, and nursing staff).

Data Analysis

Interpretive descriptive approach - in order to most effectively inform clinical practice. This involves (1) repeated immersion in the data, (2) coding, (3) classifying or creating connections and (4) interpretation.

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RESULTS

Readiness was associated with prior experience for residents and family, motivation and attitude, and clarity of roles in the process.

Prior experience:

Prior involvement in EOL care, ACP or a health crisis, were all identified by participants as paramount in shaping current perspectives.

“... after I got through that operation and got back home, I realized that there was things that people should’ve known if I hadn’t have made it through. You know?”

“... I’ve watched my mother and my dad, my sisters, you know, my brother. And to me, those kinds of things have to be planned ahead because strange things happen to people. Like my brother got ALS.”

Motivation and attitude:

Practicality. Residents displayed practicality and acceptance when it came to matters of health, the ACP process and EOL. Often, they did not wish to prolong life at any cost, rather they were interested only in limited health interventions.

“But you really do have to start thinking about this and thinking, ‘Do I really wanna have thirty days of treatment?’”

Appreciation and difficulty making decisions. FM indicated feeling very appreciative of the positive ways in which ACP had enabled them to experience their loved one’s EOL

“It meant that we were able to spend time being with him ...caring for him...the way that we knew he wanted and not worrying about what they were gonna do if something happened because they...knew that.”

Variable comfort and ethical conflict. Variability in comfort with conversations and thical dilemmas were associated with ACP readiness in the SL setting for clinicians.

“I’m a little bit unsure...sometimes I feel we push...and I’ve been challenged a little bit on the team here because...I’ve actually been told that anyone coming in here must have it.”

Role clarity in ACP:

Residents and family members had a clear understanding of their roles in the ACP process. Clinicians acknowledged their roles in ACP but also expressed uncertainty about who is ultimately accountable for which role. As one clinician explained:

“...I really think that the multi-disciplinary team don’t know... there’s this huge role.”

INTERPRETATION

In order to capitalize on the impact of experience, clinicians can take the approach of explicitly inquiring about and using prior experience of decision-making or EOL as a launching point for conversations.

A lack of clarity in roles and accountability for initiation of ACP or GCD conversations emerged as a theme. In order to improve clinician confidence and ease the burden of uncertainty, health services should design and implement a comprehensive guide for how (and by whom) ACP should be ideally conducted in the SL setting.

Some clinicians indicated that residents can be pushed to complete medical order (GCD) documents even when they may not wish to do so. Although completion of these documents eases the burden of responsibility on clinicians, forcing residents to complete voluntary documentation overrides respect for their autonomy and dignity. Optimal care and respect for resident dignity and autonomy might instead involve a shift in clinician focus, away from GCD completion as a primary goal, and towards increased understanding of residents’ goals, values, wishes and preferences.

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