

Project Title

Barriers To Participation in Advance Care Planning for Next-Of-Kin of Nursing Home Residents: A Multi-Method Evaluation

Project Lead and Members

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Organisation(s) Involved

National Healthcare Group, Tan Tock Seng Hospital, Woodlands Health

Healthcare Family Group(s) Involved in this Project

Allied Health

Applicable Specialty or Discipline

Palliative Medicine

Project Period

Start date: Not Available

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Aims

Project RESpecting Preferences, Empowering Conversations Together (RESPECT) aims to support nursing homes (NHs) in the Central region in Singapore, to implement and sustain the practice of Advance Care Planning (ACP).

Background

See poster appended/ below

Methods

See poster appended/ below

Results

See poster appended/ below

Conclusion

See poster appended/ below

Additional Information

Singapore Health & Biomedical Congress (SHBC) 2023: Best Poster Award (Health Services Research) – (Gold Award)

Project Category

Care Continuum

End-of-Life Care, Palliative Care, Hospice Home

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Palliative Care, End-of-Life, Awareness, Advance Care Planning, ACP

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Barriers to participation in Advance Care Planning for next-of-kin of nursing home residents: a multi-method evaluation

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BACKGROUND

- **Project RESPECTing Preferences, Empowering Conversations Together (RESPECT)** aims to support nursing homes (NHs) in the Central region in Singapore, to implement and sustain the practice of **Advance Care Planning (ACP)**.
- As many residents in the NH are cognitively impaired and lack decision-making capacity¹, their next-of-kin (NOK) would participate in facilitated ACP discussions as their **Nominated Healthcare Spokesperson (NHS)**, and make end-of-life (EOL) care decisions on their behalf.
- Nonetheless, these NOKs **may not want to participate** in these discussions, due to a low awareness of ACP or difficulty in broaching the topic with the sensitive and taboo nature of EOL issues.²
- Among those who eventually agree to participate, barriers to having a productive discussion may include a **lack of readiness and confidence** to make the required decisions.
- Furthermore, as these decisions are often based on limited information and uncertainty, NOKs may also experience **decisional conflict towards their options**, which would inhibit their ability to come to a clear choice during the discussion process.
- Hence, to facilitate the successful initiation and completion of ACP discussions in the Project RESPECT NHs, we aimed to identify **barriers faced by NOKs in the process of engaging in ACP** on behalf of the resident.

METHODS

A multi-method evaluation approach was adopted.

Interview with NH ACP leaders

- **One-on-one interviews** were conducted with NH management leading ACP within their institution
- Interviews were recorded and transcribed verbatim, and thematic analysis was used to derive themes and sub-themes
- **Barriers to ACP for NOKs** as perceived by the leaders were reported

Survey of NOKs

- NOKs who agreed to a scheduled ACP discussion were surveyed prior to starting the session (**Table 1**)
- **NOKs' readiness and confidence to participate** in ACP as an NHS, and the types of **decisional conflict** they felt were reported

Table 1. Questionnaires used in the survey

ACP Engagement Survey ³	Decisional Conflict Scale ⁴
<ul style="list-style-type: none"> ▪ 10 questions on readiness and confidence in engaging in processes related to ACP for both their family member and themselves ▪ Number of participants who indicated they were ready (R) or confident (C) in each question were reported 	<ul style="list-style-type: none"> ▪ 10 questions across 4 domains of feeling uninformed, unclear about what they valued, unsupported and uncertain towards EOL care options for their family member ▪ Frequency of responses across the 4 domains were reported

RESULTS

Barriers to NOK involvement in ACP

The 6 NH ACP leaders cited 3 barriers:

- **The low public awareness of ACP**, its intention and implications;

"When people mention, you're not doing anything for my father anymore (...), the perception comes because there's no awareness about ACP in the community." (IDI4)

- **Death avoidance**, where NOK are hesitant to talk about death as a way of reducing anxiety about it or because it is a cultural taboo;

"That is the main thing that we have problem with, they say that "my father is still ok what"....they don't need to go through that." (IDI2)

- **Burden of surrogate decision-making**, where NOKs have to be accountable for and negotiate with other family members on the care decisions

"So some family members, they will directly tell to us that this is the problem, "I don't want to take a decision. So, we will just collectively take the decision. If anything, you just call me and I will check with my other family members and let you know." (IDI5)

ACP engagement

Among the 67 NOKs who agreed to a discussion, most were:

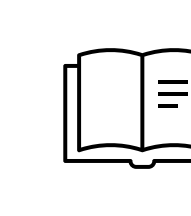


- **ready and confident to talk to doctors** about care preferences for their family member [R: 52 (78%), C: 47 (70%)]



- **ready to sign official papers** to put their family member's preferences in writing [R: 47 (70%)], and appoint themselves as the NHS [R: 48 (72%)]

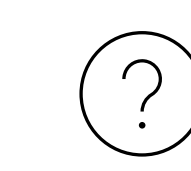
Decisional conflict



- **61%** or more of participants reported feeling **uninformed about the available care options, and their benefits, risks and side effects**



- **55%** or more felt **unclear about which benefits, risks and side effects** mattered most to them



- **42%** or more felt **uncertain** about the decisions they were to make



- **28%** or more felt **unsupported** in their decision-making process

DISCUSSION & CONCLUSION

- Some NOKs were **unaware or unwilling** to engage in ACP due to personal attitudes, and participants starting a discussion felt **uninformed and unclear**.
- While increasing awareness of ACP would be fairly straightforward, **changing perceptions of ACP** as taboo or the reluctance of NOKs to serve as a decision-maker would require **more time and effort**.
- Hence, interventions to increase ACP uptake in NHs **must target barriers specific to each segment**, and support from facilitators and healthcare institutions will be key to ensuring their success.

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Recommendations

To increase uptake of ACP among NOK of NH residents

- Normalise ACP through creation of awareness in the general public or through primary care

To increase readiness and confidence of NOKs to make EOL care decisions

- Provide layman explanations to NOKs, on the available options and their implications during the ACP facilitation process
- Guide NOKs to articulate plainly what they would perceive as important to their family members at the EOL