Faith impacts Advance Care Planning
A Focus Group Study of Catholic Women's perspectives on ACP

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Advance Care Planning Collaborative Research & Innovation Opportunities Network

BACKGROUND

- Achieving advance care planning (ACP) at a population level requires an understanding of how ACP is received by diverse socio-cultural groups.
- Little is published about how faith or religious beliefs interact with ACP.
- As part of a study to understand the readiness, barriers and facilitators to engage a population in ACP, we interviewed Catholic women in Alberta, Canada.

METHOD

- Two focus groups, total 17 women (predominantly Caucasian, middle-aged, range 20's-70's)
- Recruitment via email invite to members of the Catholic Women's League of Alberta
- Qualitative analysis using Glaserian Grounded Theory
- Semi structured interview guide, included one question about "religion." This was changed to "faith" based on responses from the first group. "In what way does your faith guide you in planning for your future health or when facing medical decisions?"

RESULTS

"My faith is, my belief is…it is life, from conception to natural death…So, a hundred percent of my decisions are made by my faith."

Statements of faith underpinned all three core categories that emerged:

Understanding of ACP

Participants shared narratives and sophisticated knowledge of what ACP is and why to engage in ACP.

"Deciding what your beliefs are, with regard to end-of-life care, um, who you travel with – trust at a point where you can't speak on behalf of yourself "

"So when I was completing my living will, I had – I really had to think about that. If – if I agree to be put on a machine at this point, if I agree not to – and then the question came up from my daughter – but what if you say you don't want that care, and they come up with a cure in a week? I said, "the good Lord'll keep me going for a week. Don't worry about it. So, a hundred percent of my decisions are made by my faith."

"Well, my mom lived in a nursing home for about five years,... following her stroke and broken hip and another stroke…but before she went in to the hospital with any of these things, she did do a personal directive, and we knew she would just want to be kept comfortable. So I mean, she had her ups and downs over those years. But when she finally was dying, we felt comfortable that we knew she – you know, we'd done everything we could – could, to keep her going and to keep her comfortable at the end. And I'm glad she had that, because it gave us peace of mind"

"What I know about it, is that um, it's a good idea to have it done on paper, legally. To um, ah, ask for what you want in case that something happens to you, ah, where you can't speak and how you would like to be taken care of at that point."

Concerns about ACP

Along with this understanding were related concerns about how ACP is acted on e.g. hospitals may not honour faith-based wishes, family decision-makers may variably interpret a person's wishes and changing one's mind.

"And also, with society the way it is, um, I find it really vulnerable to think about going to the hospital. 'Cause even in the Catholic hospitals, they're not always ah, going according to the Catholic principles"

"My beliefs are whatever – morality that I have or think I have, affect my decisions. Um, I also think, um my relationship with my family also affects I think, probably how I'm going to make my decisions. 'Cause I'll have to decide who – who's going to be my alternate voice. Um, so you – you have to look at your relationships as well, within your family. Beliefs but also family relationships impact decision making. Including choice of agent."

"But I put my eldest daughter in [the personal directive]. And she's actually not Catholic. So I should maybe put my youngest daughter, who is."

"How much value does it have? How much does it hold? And can a – a spouse say, "no, I want you to – you know, go against it. And I want you to revive him."

"You might make a decision. How um… final is that decision? Because in the process of dying, you might think, I don't want that now."

Death and Dying

Profound tensions were evident about suffering, the role of opioids, assisted suicide, life prolonging therapies, interpreting God's plan through medical interventions and the actions of clinicians but not acceptance of death itself.

"Biggest issue, I know for Advance Care Planning and right now is euthanasia, and assisted suicide in Canada. Um, so I think those are discussions that I know I need to have with my families, um, I have seen where I believe sometimes, morphine is used in excess, at the end of life. And I do have concern with that as well"

"And the feeling is like God is the one that brought us, and God will be the one taking us. And the less we interfere, the better off we'll be. And that goes from everything, from daily living to um, natural family planning, to planning the death – you know, a natural death. Natural birth, natural death."

"Even if you are strong in your faith, which I am, I still think that… why would I suffer? You know, for no reason. We've got the medicine. There's no – not to be euthanized, don't get me wrong. But –"
"But to go gently, and then – yeah."
"And something can be done for the physical suffering. The existential suffering is worthy."

"It's a scary thing, but I'll have faith and I think, when the good Lord calls me, then I'll go, and hopefully I'll get all this stuff organized before he calls me. So, I'm not scared of death.

CONCLUSION

The depth of understanding was quite different from other faith groups we have studied (Biondo, Health Expect 2016) but themes were similar to those of nuns in Singapore (Tan, AJHPM 2017). Our approach for clinician training and engaging the public in ACP has been adjusted to reflect this new awareness of the varied understandings, concerns and tensions in our population.

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