A cross-contextual exploration of factors influencing interpretation and uptake of local ACP policy

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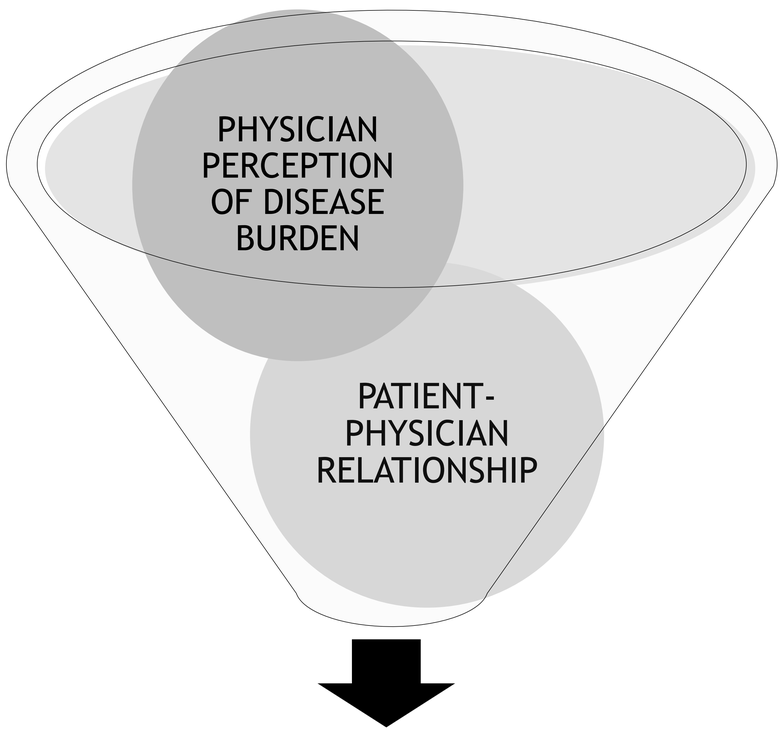
Background:
Little is known about how *disease context* may uniquely influence attitudes, approaches and processes of ACP engagement for patients and clinicians.

Objective:
Using cross-contextual data we explored disease context influences on ACP practice to generate strategies to enhance the uptake and quality of ACP with respect to contextual factors.

Method:
- Qualitative interpretive descriptive (ID)[1] design, applied to multi-perspective study
- Data collection consisted of 1:1 semi structured interviews with participants. Interviews were recorded and transcribed for analysis.

Participants		
	Patients	Clinicians
Supportive Living	10	9
Heart Function out-patient clinic	8	9
Renal out-patient Clinic	7	6
Cancer out-patient clinic	8	9

Findings :
Four main themes emerged from the data: Common to all 4 contexts were: 1. Lack of shared understanding between patients and clinicians and 2. A lack of consistent ACP process. We found that ACP understanding and process varied between contexts, driven by 3. Disease burden and 4. The nature of the physician-patient relationship.



- **LACK OF SHARED UNDERSTANDING OF ACP**
- **VARIABLE AND INCONSISTENT ACP PROCESSES**

PHYSICIAN PERCEPTION OF DISEASE BURDEN

Physician perceptions of disease burden were an important conversation driver that impacted timing and function of ACP.

Context	Timing	Function
HEART FAILURE	Ongoing	Determine treatments/ interventions currently and throughout illness trajectory/health decline.
BONE MARROW TRANSPLANT	Change in health status (associated with treatment failure)	Determine how end-of-life care would be provided.
RENAL	Substantial or acute health decline near end of life	Aid in planning for end-of-life.
SUPPORTIVE LIVING	Worsening frailty	Determine treatment plans based upon evaluation of physical functioning.

There might be patients who I meet the first time I'd say, "...you have a very aggressive lymphoma. I'm not sure this [transplant] is going to work. At some point if things aren't working, we're going to have a different discussion'...So for some patients it's really obvious I can do that and then others,' No, we're still heading into cure' and I don't have to talk about the negatives"(Physician, BMT)

We have a lot of elderly patients with chronic illnesses. And in those patients it's really important that they understand what's likely to happen to them as their disease progresses.'(HF, Nurse)

If I feel like patient I don't see very good prognosis... that death is to happen in a very near future...then I absolutely need to bring up earlier. (Renal, Physician)

I think probably then is the time, you know if it's been awkward up 'till this point, I think for sure here going to hospital, you know if you're over 75 and you've been in the hospital twice in the last year, I mean if you haven't had the conversation, you probably should. (SL, Physician)

PATIENT-PHYSICIAN RELATIONSHIP

Allied healthcare professionals tend to emphasize the importance of providing support and understanding a patients' values. Conversely, many physicians described taking a directive role in the relationship, focusing on the specifics of illness and treatment options or availability.

"I'm gonna continue to bring it up at every single meeting until we get this document because this is just really important for us to know." (Renal Physician)

"Well, I don't offer them a carte blanche here. Usually, I tell them about the disease...different ways of dying...and..options....but I wouldn't discuss transplant in someone who's 80 years old and has renal failure...so I don't offer options that are not really available for that patient". (HF Physician)

"I would say..do you know about this program, and it could maybe ease your family and yourself...reduce the stressors...if you can plan ahead as to how you would want things done". (HF Nurse)

LACK OF SHARED UNDERSTANDING OF ACP

'advance care planning' was not familiar to patients (despite thoughtful approach to key ACP steps (thinking, discussing, documenting)). Clinicians expressed a complex understanding of ACP terminology and activities.

"Yeah, we have done that...we have our funeral arrangements all made." (SL, Patient)

"We've gone through the process of arranging our, what do they call it, the finances and I believe the health issues if we're unable to make decisions." (Renal, Patient)

"...originally, I thought it was something that got you right to the resources, but now I understand it's a way of thinking, a way of managing, way of preparing family and the patient to think about what they want to do for the next stage of their life". (HF, Dietician)

VARIABLE AND INCONSISTENT ACP PROCESSES

Variability in ACP processes was found both within and between contexts. Although HF, SL and Renal settings relied on multidisciplinary teams to conduct ACP, participants expressed role confusion and inconsistency in passing ACP tasks among member of the clinical team. In BMT, ACP was strictly the role of the physician, which was embraced by some physicians while others expressed discomfort.

'we have an advanced care planning nurse so we kind of let her do her thing," (Renal physician)

"we make sure that once a year the patient comes in to see their nephrologist that the goals of care are up to date... and if they're not just letting the nephrologist know, so then that nephrologist can have that conversation with the patient." (Renal Nurse)

"It's just like anything else. Uh, do you have an allergy? Are you on any medications? What are your goals...what do you want us to achieve here?" (BMT Physician)

"They don't know whether - how far they should go, what they should do." (SL Nurse)

"The heart failure clinics are very structured...different aspects of patient care are done in a standardized fashion. So nursing, I'm certain...approaches patients about that early on...whether that happens on the first encounter, we're not sure' (HF physician)

Discussion:
Intent of ACP policy to encourage conversations with healthy adults and patients early and in an ongoing fashion is not yet being realized.
- Uncertainty around illness course and clinician beliefs on appropriateness of treatments key in evaluation of disease burden & timing of conversations.
- The need to know patients' values and wishes did not appear to be a major driving force for conversations.
- Tension between the desire to reduce practice variance and to support contextual adaptation for any policy implementation.

Recommendations:
To achieve intended policy goals or early, routine ACP and high quality patient-centered goals of care designations
- Quality improvement methods can be employed, to identify current processes, gaps and strategies for developing a consistent comprehensive process.
- Promote use of serious illness conversation guide to drive and structure ACP conversations with patients[2].

Acknowledgements:
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References:

[1]Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice* (Vol. 2). Routledge.

[2] Bernacki, R. et al., (2015) Development of the Serious Illness Conversation Guide. BMJ Open.

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