Drivers, Navigators, and Passengers:
how do those living with advanced complex chronic diseases want to self-care?

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Objective
To determine the barriers and facilitators of self-care when living with an advanced stage complex chronic disease, and to understand the potential of an interactive care pathway to support patients in their self-care when living with an advanced stage complex chronic disease.

Context
Patients with advanced stage chronic diseases, often characterized by high rates of hospitalization or aggressive use of treatments with limited benefit, present significant challenges. These patients have extensive care needs as they transition between hospital and home and require extended health care planning and support. However, the health system is complex and often overwhelm patients and caregivers.

Methods
World Café Methodology
Enables participants to interact, share experiences, explore issues, identify gaps & working solutions, and inform implementation strategies.

Participants
Patients (n=12) living with, and caregivers (n=4) caring for a patient with, advanced chronic diseases from both rural and urban areas across Alberta. The majority of the patient participants were living with cancer-related illnesses. Others were living with end-stage kidney diseases, fibromyalgia, dementia/Alzheimer's, and neurological diseases.

Key Takeaways
- The health system is complex and difficult to navigate, even those who feel empowered struggle to advocate for themselves within this complex system
- Gaps in knowing how to access and use information, how to get to appointments, and what resources are available
- Health care provider’s unspoken expectations of a patient’s ability to self care

Facilitators that would enable self-care:
- A need for relational continuity: provider needs to take time with patient; understand patient is unique and has distinct wishes they want heard and respected
- Care and treatment being disease focused
- That a care pathway could be beneficial if it is interactive, accessible to all involved, and personalized to each patient

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