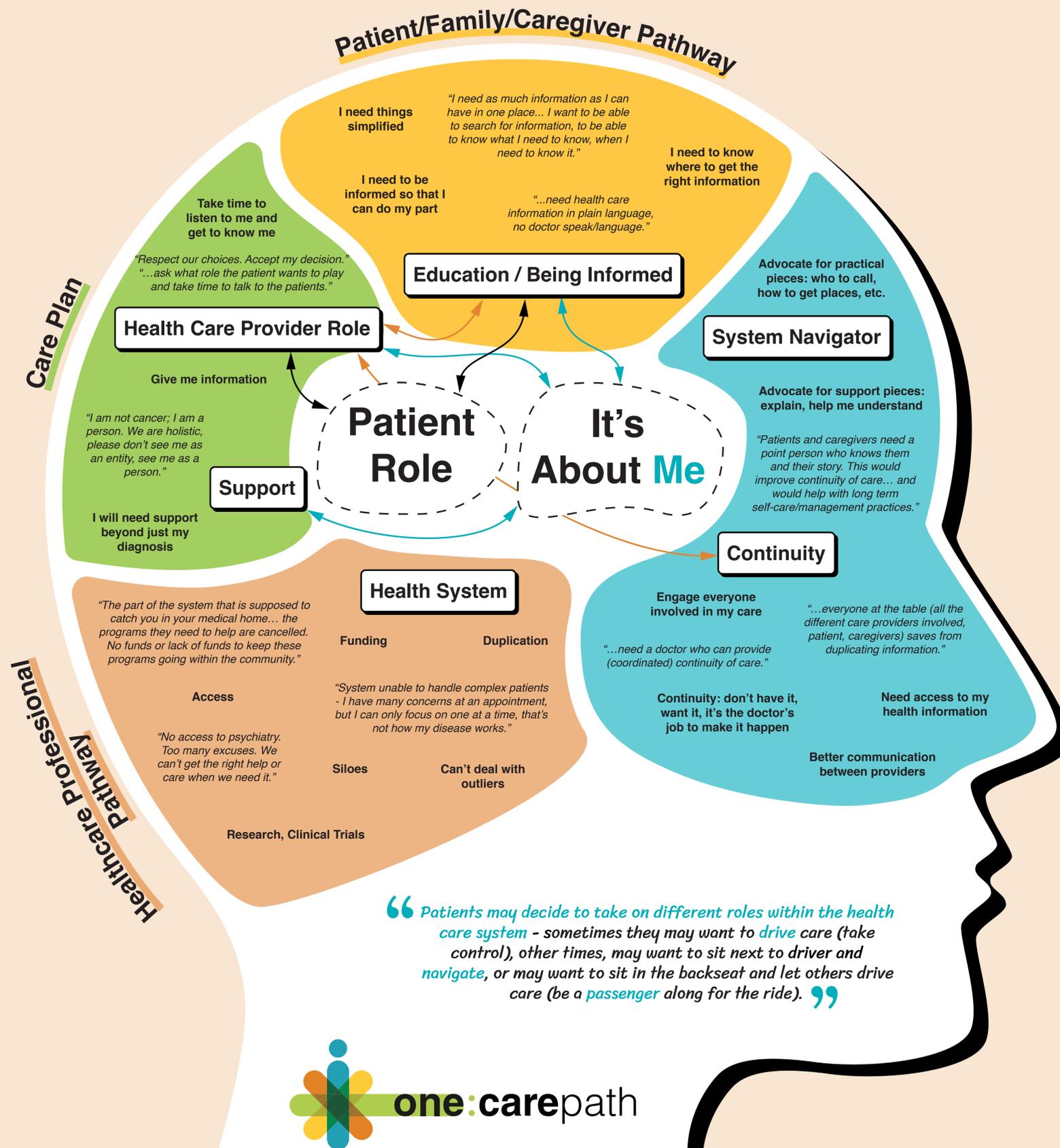


# Drivers, Navigators, and Passengers: how do those living with advanced complex chronic diseases want to self-care?

Toon L., Barber T., Lakusta B., Scott K., Davison S., Green LA.



## Key Takeaways

In the context of self-care, patients described barriers that make self-care difficult:

- |  |   |  |
|--|---|--|
| <ul style="list-style-type: none"> <li>The health system is complex and difficult to navigate, even those who feel empowered struggle to advocate for themselves within this complex system</li> </ul> | <ul style="list-style-type: none"> <li>Gaps in knowing how to access and use information, how to get to appointments, and what resources are available</li> </ul> | <ul style="list-style-type: none"> <li>Health care provider's unspoken expectations of a patient's ability to self care</li> </ul> |
| <ul style="list-style-type: none"> <li>Variation in how active they want to be in their self-care</li> </ul>   | <ul style="list-style-type: none"> <li>Care and treatment being disease focused</li> </ul>  |  |

Facilitators that would enable self-care:

- |  |   |
|--|---|
| <ul style="list-style-type: none"> <li>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</li> </ul> | <ul style="list-style-type: none"> <li>A need for access to resources and information to play a more active role and make informed decisions</li> </ul>                       |
| <ul style="list-style-type: none"> <li>A need for support in navigating the system – a System Navigator Role</li> </ul>  | <ul style="list-style-type: none"> <li>That a care pathway could be beneficial if: it is interactive, accessible to all involved, and personalized to each patient</li> </ul> |

## 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 unmet care needs as they transition between hospital and home and regularly return to hospital. This results in poor quality of life for patients, frustration, and rework for health care providers with increased costs to the health system.

## Methods

### World Café Methodology

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

Organized in small groups at four tables, participants rotated between all tables. Each table had a set of questions and assigned facilitators and note takers to record the discussions. Notes were transcribed verbatim for analysis.

### Framework Analysis

Is grounded in original accounts, attempts to answer specific questions, and is best applied with a specific sample population. Its goal is to answer pre-determined questions. It was well suited to analyzing the World Café data, and the interpretation of our results.

## Participants

Patients (n= 12) living with, and caregivers (n= 4) caring for a patient with, advanced chronic disease 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 disease, fibromyalgia, dementia/Alzheimer's, and neurological diseases.

## 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.



If you have any comments, questions or would like to request a print copy of this poster, contact Lynn Toon [lynn.toon@albertadoctors.org](mailto:lynn.toon@albertadoctors.org)