

1. PROBLEMATIZATION: SELF-CARE IS A CHALLENGE

The Challenge of Self-Care for people living with Parkinson's (PWPs)

- Two million people are living with Parkinson's disease or a parkinsonism in Europe and Canada, a number that is rising significantly with population aging (Espay et al., 2019).
- Health technologies show promising potential to support self-care in Parkinson's (Lee et al., 2022; Silva de Lima et al., 2020; Riggare et al., 2021)
- However, PWPs report that the unpredictability and variability of symptoms make it difficult to selecting self-care goals, and that they often lack structured guidance to achieve them (Tonnesen & Nielsen, 2023).

2. OBJECTIVES: SET SELF-CARE GOALS

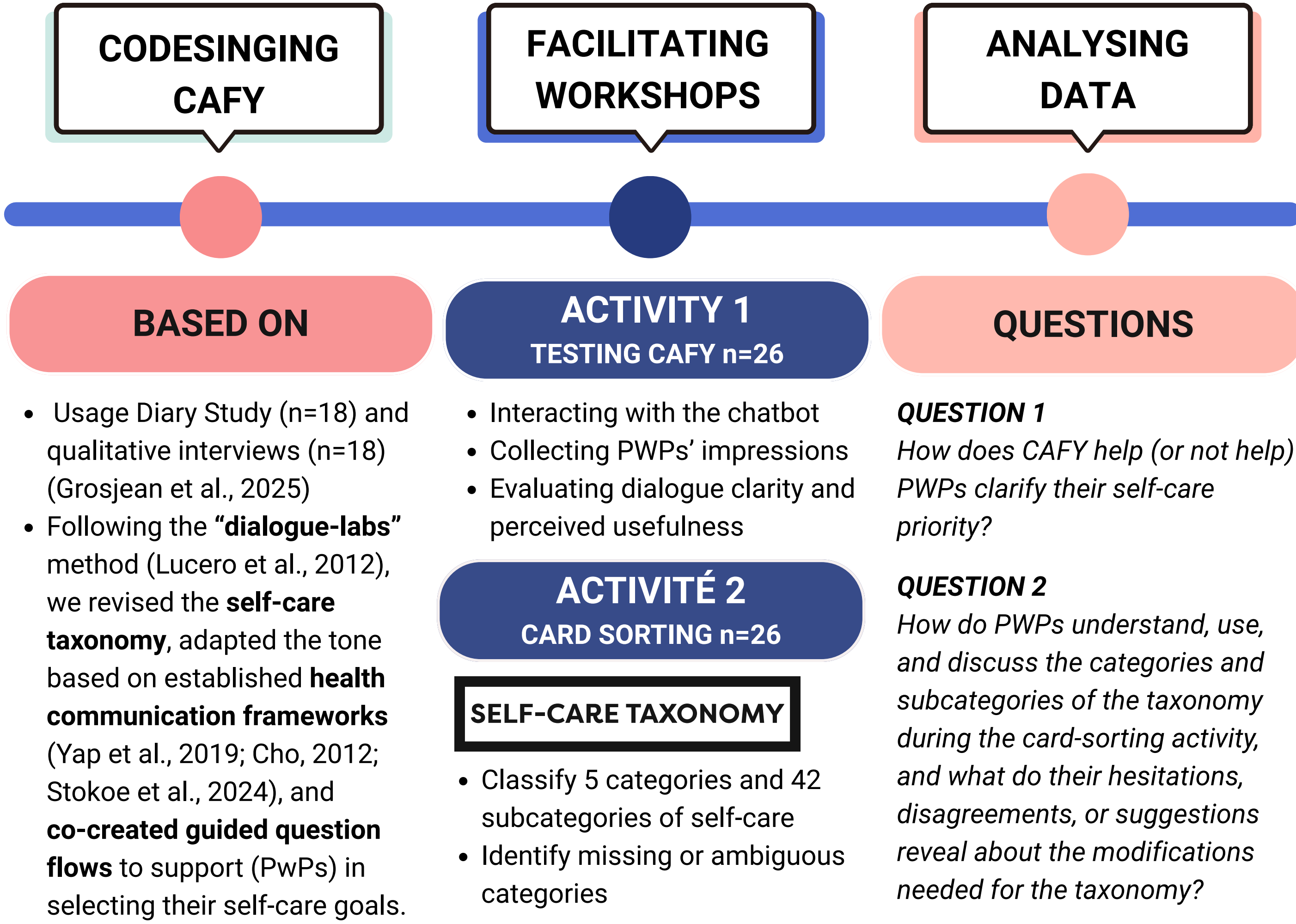
Primary Objective

- To develop and evaluate CAFY (Conversational Assistant For You), a structured chatbot that helps PWPs identify their priorities and formulate personalized self-care goals.

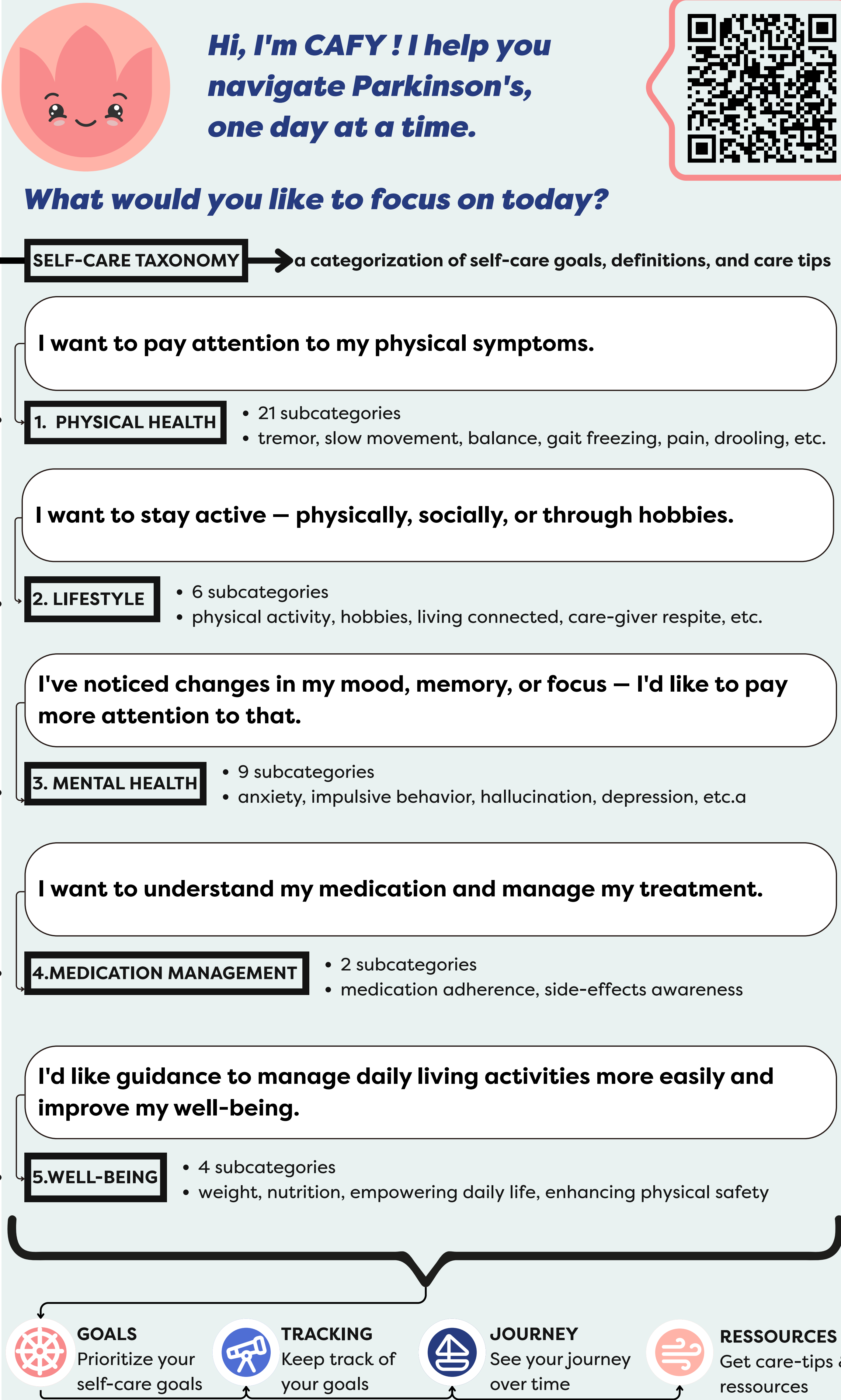
Secondary Objective

- To use CAFY as a design probe to inform the future development of an AI-based conversational recommender system.

3. METHODOLOGY: CODESIGNING WITH & FOR PEOPLE LIVING WITH PARKINSON'S



TESTING CAFY: A STRUCTURED CONVERSATIONAL CHATBOT



4. PRELIMINARY RESULTS ANALYSIS:

We conducted a reflexive thematic analysis (Braun & Clarke, 2019; Byrne, 2022), collaboratively interpreting the data and focusing on depth of interpretation.

ACTIVITY 1: TESTING CAFY

WHEN CAFY SUPPORTS GOAL SETTING	WHEN IT FAILS TO SUPPORT GOAL SETTING
Offering conversational or list views that align with the user's thinking style	Requiring physical actions that motor symptoms make difficult (tapping, navigating, voice input).
Helping patient-caregiver co-interpret experiences and negotiate priorities	Creating uncertainty through unclear onboarding, missing back button or unclear progress cues.
Enabling self-reflection ("Oh, that's me!). Participants notice symptoms, make sense of changes, and clarify priorities	Presenting unclear categories that leave users unsure what applies to them.
	Delivering a long final list without filtering or ranking options.

ACTIVITY 2: SELF-CARE TAXONOMY CARD SORTING

RESTRUCTURING THE TAXONOMY IN 5 DOMAINS BASED ON PATIENT INTENTIONS	RETHINKING THE TAXONOMY BASED ON FIVE PATIENT CONTINUUM LOGICS
Experiencing physical symptoms & body changes	1. Perceived Cause Logic: based on perceived origin (physical, disease, medication).
Navigating mood, memory & focus	2. Effect Logic: based on experienced effects (well-being, social life).
Staying active & engaged	3. Disruptive Impact Logic: based on the most disruptive impact on daily life.
Managing medication & care	4. Emotional Impact Logic: based on psychological and cognitive impact.
Handling daily tasks, transition & independence	5. Autonomy & Quality of Life Logic: based on the impact on daily functioning.

4. CONCLUSION:

- Findings indicate that CAFY shows promise in supporting the prioritization of self-care goals in daily life.
- Findings enhances the self-care taxonomy, generating insights for future AI-based conversational recommender systems



REFERENCES