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## INTRODUCTION

- Parkinson disease (PD) symptoms progress over time, resulting in cumulative disability and loss of independence (LOI).
- Information on the longitudinal patterns related to LOI in PD patients is limited.

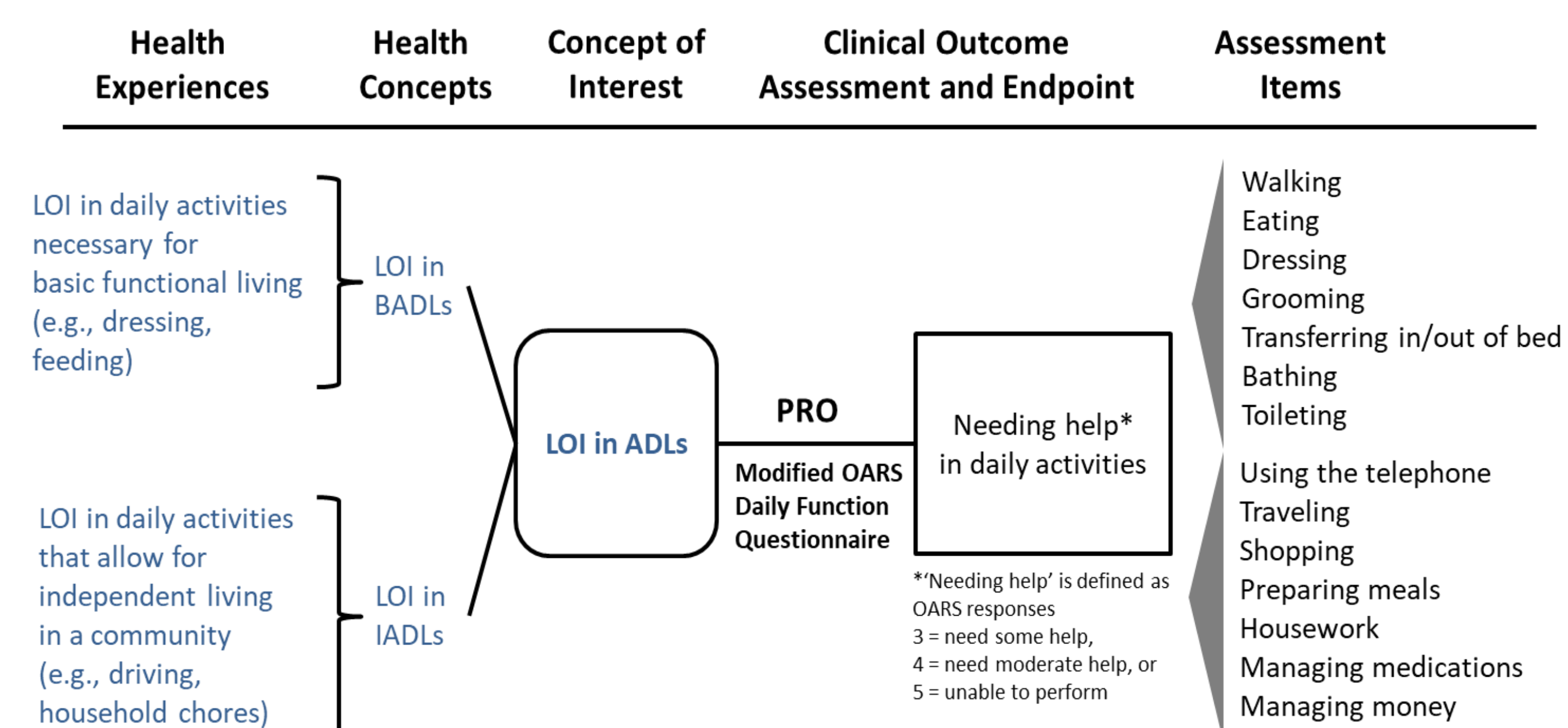
## OBJECTIVE

- To characterize the longitudinal development of LOI in PD using data visualization software.

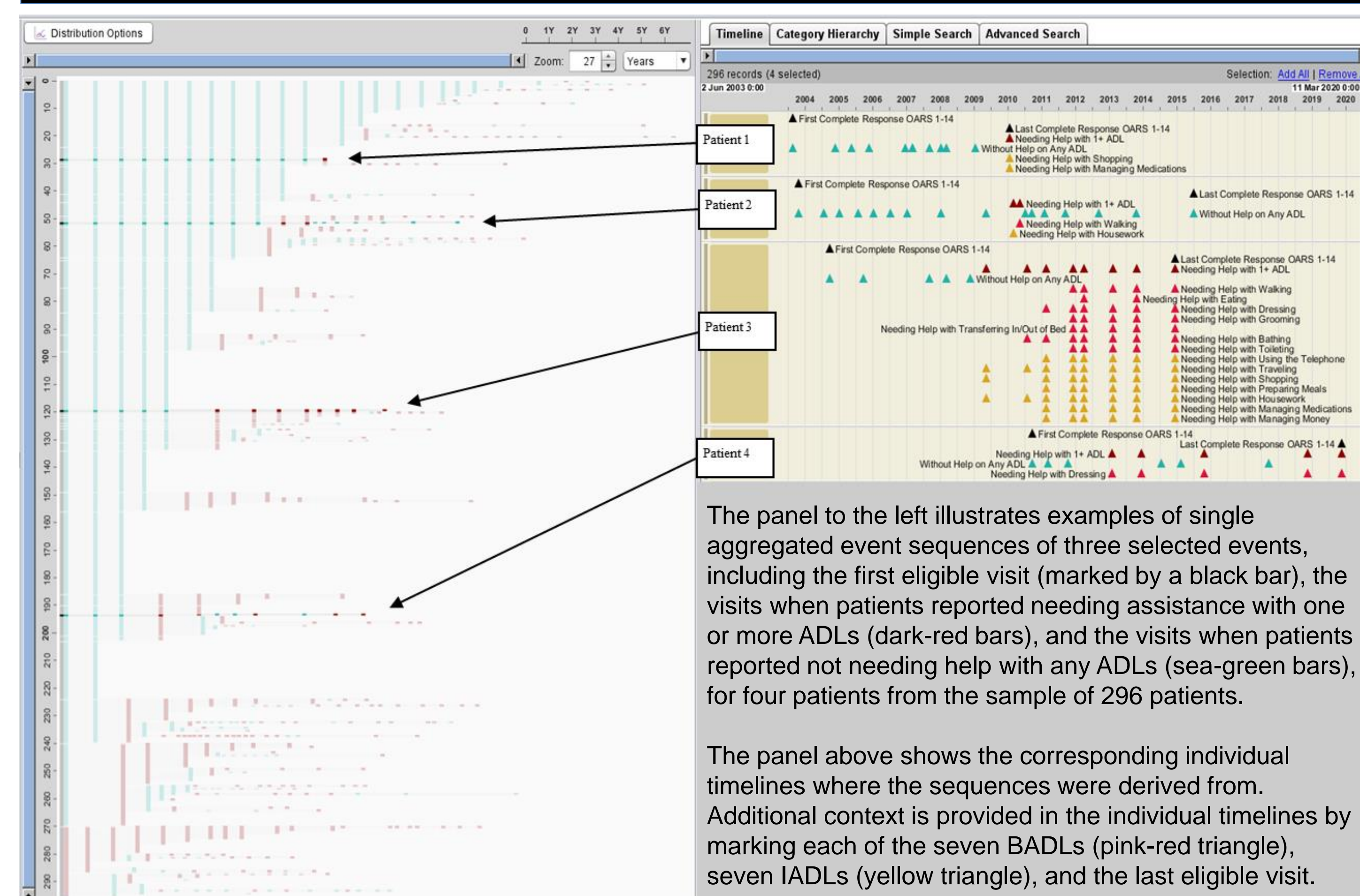
## METHODS

- This longitudinal study utilized data from a prospective naturalistic cohort study of PD patients seeking care at a tertiary neurologic center.
- Eligible patients were diagnosed with early-stage PD and received care from a movement disorders specialist during visits that occurred between 2003 and 2020.
- LOI was defined as needing help with activities of daily living (ADLs) based on patient-reported data collected using the modified Older Americans Resource and Services Daily Function Questionnaire at baseline and follow-up visits.
- **Figure 1** shows the conceptual framework for measuring LOI in this study.
- EventFlow data visualization software was used to display and summarize longitudinal patterns of LOI in basic ADLs (BADLs) and instrumental ADLs (IADLs).

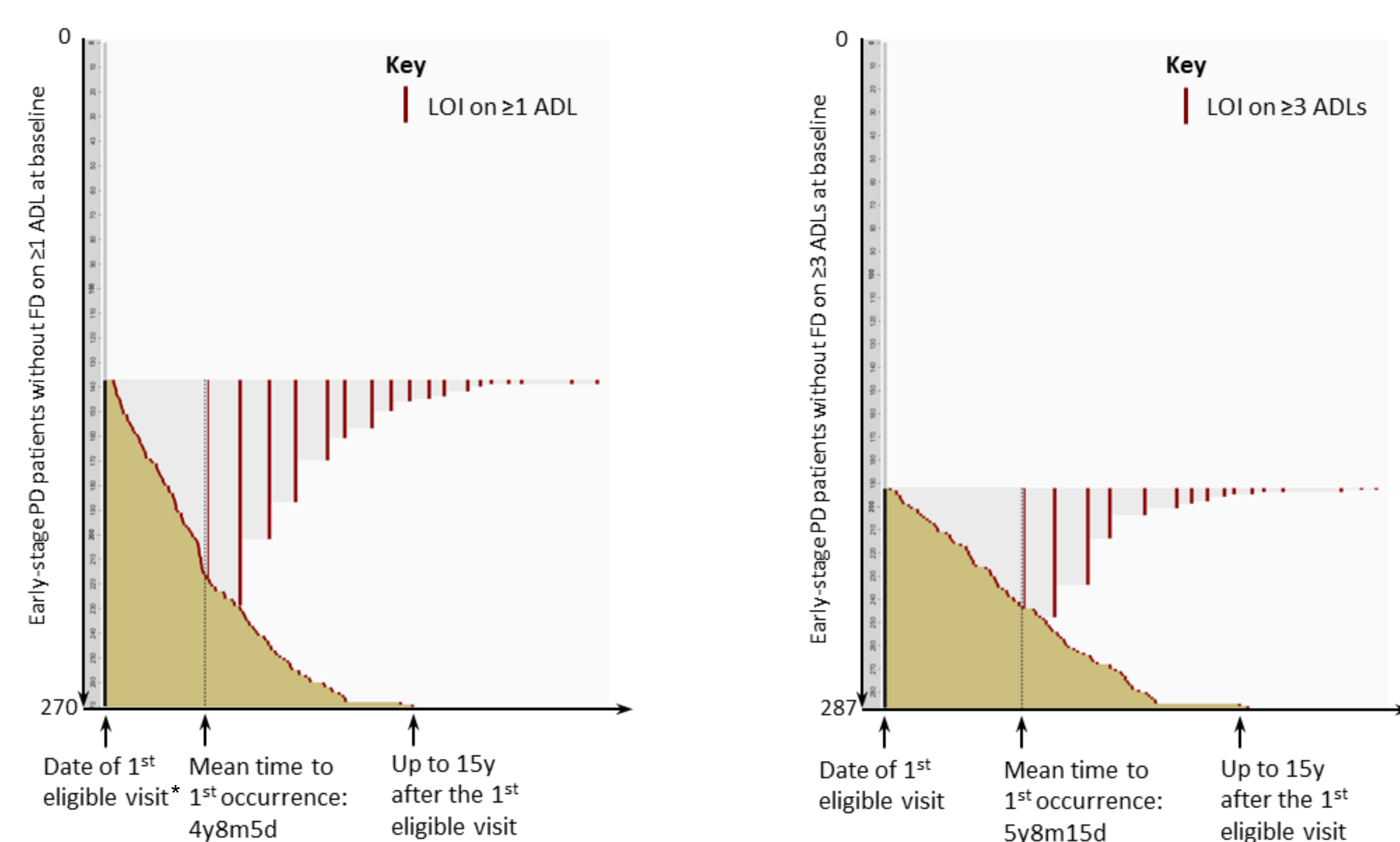
**Figure 1: Conceptual Framework for Measuring LOI in ADLs**



**Figure 2: Example of the EventFlow Visualization Process**



**Figure 3: Incidence and Timing of the First Reported LOI**

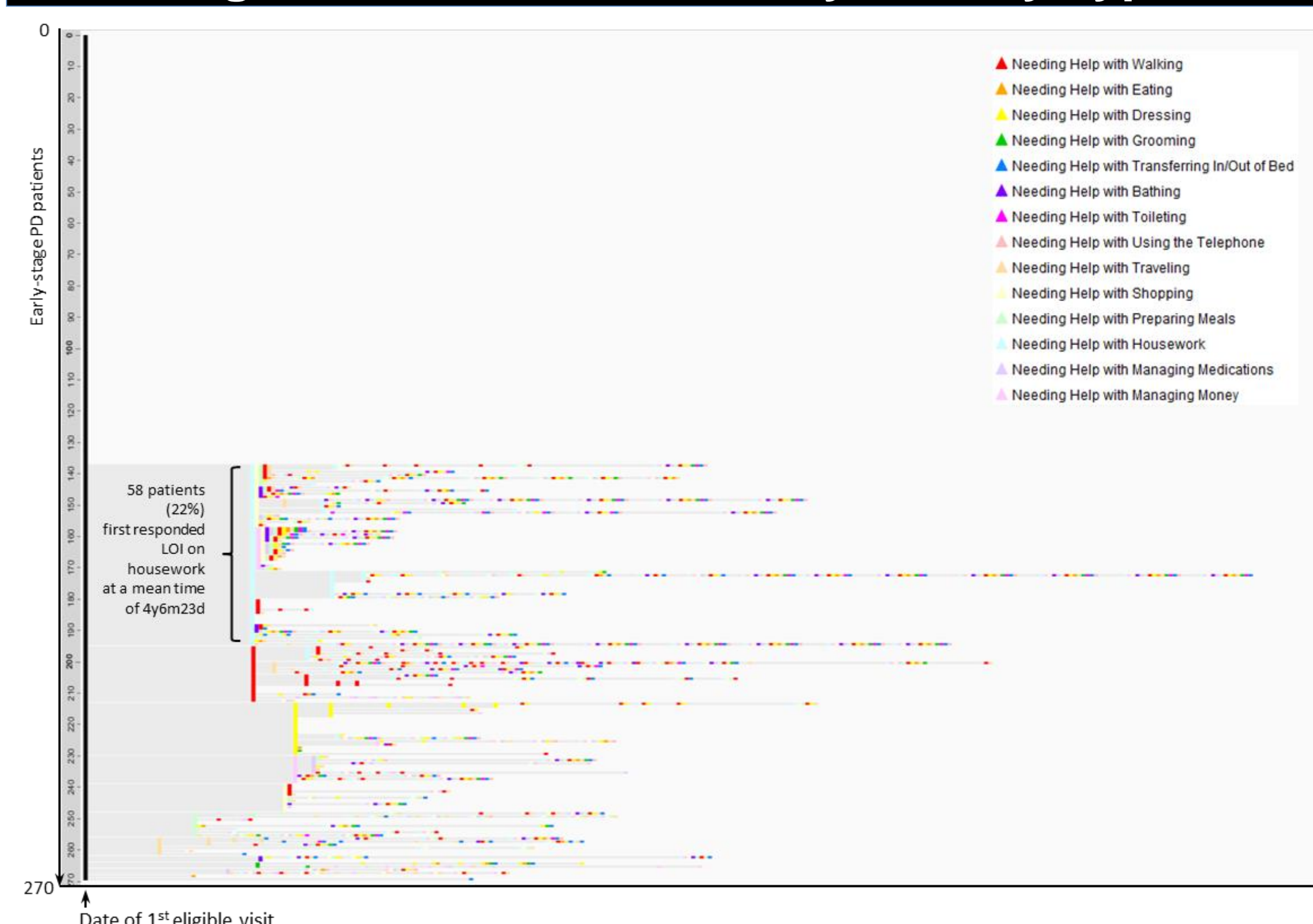


\*Eligible visits are defined as visit records with complete responses across 14 daily function questions.

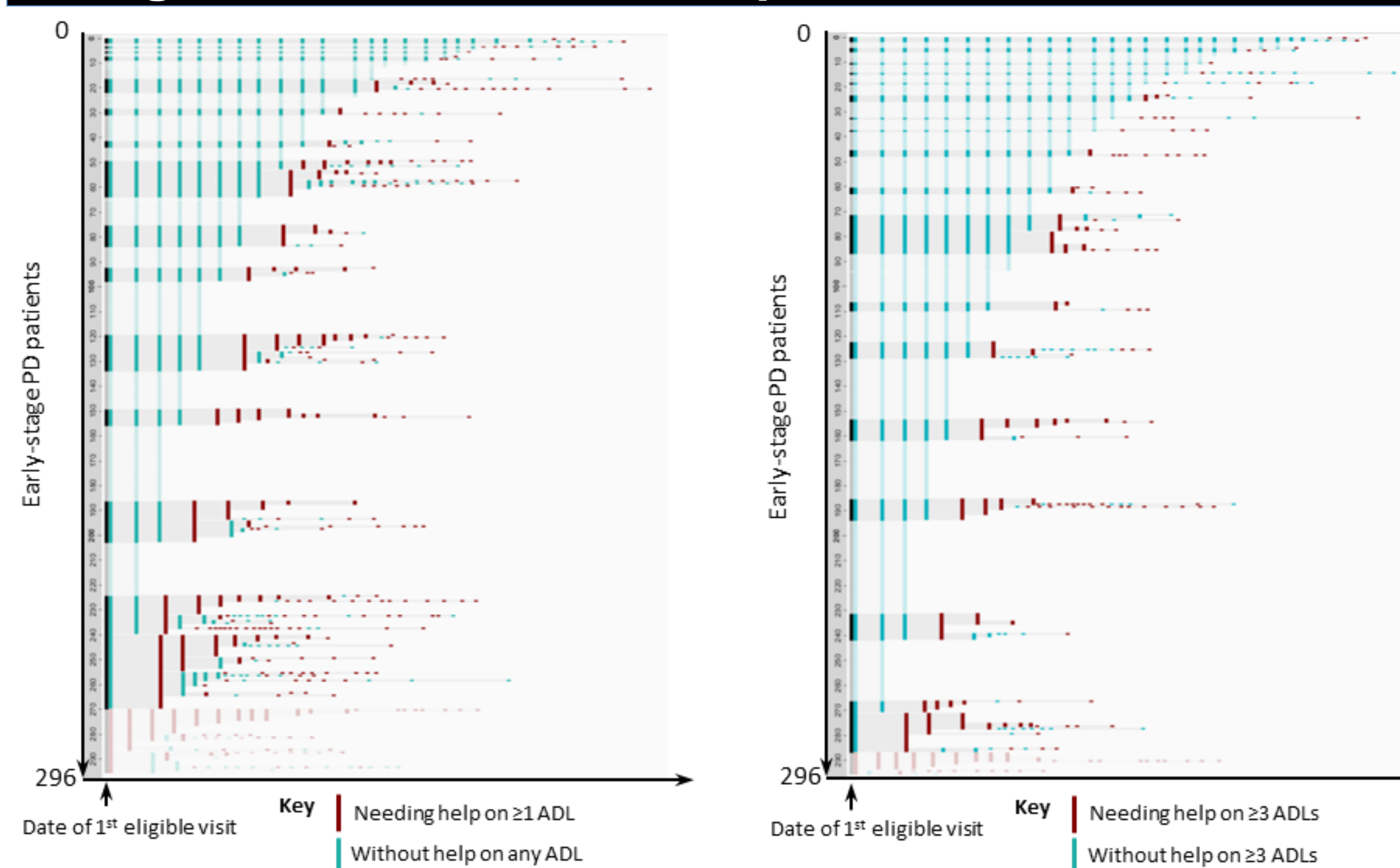
**Table 1: Baseline Characteristics (n=296)**

Characteristics	N	Col %
Age at baseline, years, mean, SD	61	10
Age at year of PD diagnosis, years, mean, SD	58	10
Young-age onset (<50)	57	19%
Middle-age onset (50 to <70)	200	68%
Late onset (70+)	39	13%
Female sex	116	39%
Race		
White	239	81%
Black/African American	9	3%
Other	12	4%
Missing	36	12%
Newly diagnosed PD	81	27%
Modified Hoehn & Yahr stage		
0/1	106	36%
2	176	59%
2.5+	14	5%
UPDRS motor score, mean, SD	13	4

**Figure 4: Patterns of LOI by Activity Type**



**Figure 5: Patterns of Independence Fluctuations**



## RESULTS

- Median duration between two subsequent visits was 8.4 months (mean: 14.1; range: 1.6 to 103.5). Patient characteristics were presented in **Table 1**.
- **Figure 2** contrasts four example individual event timelines and their corresponding aggregated event sequences.
- LOI on  $\geq 1$  ADL and on  $\geq 3$  ADLs were identified in 49% and 33% of the respective sample (**Figure 3**).
- The most frequent first ADL requiring help was housework in 22% of the sample at a mean time of 4.6 years following the first visit (**Figure 4**).
- Longitudinal patterns of loss were revealed, including transient and persistent loss. Of 133 early-stage PD patients who reported LOI on  $\geq 1$  ADL, 57 patients (43%) regained independence at least once after the first LOI (**Figure 5**).

## CONCLUSION

- Independence in daily functions fluctuates with patterns of both transient and persistent LOI in PD.
- Visualization of longitudinal patterns of LOI in PD offers valuable insights into the patients' experience.

## CONTACT INFORMATION

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