Inherited retinal disease (IRD) and subsequent use of homecare: Findings from the Swedish national registers 2001—2021

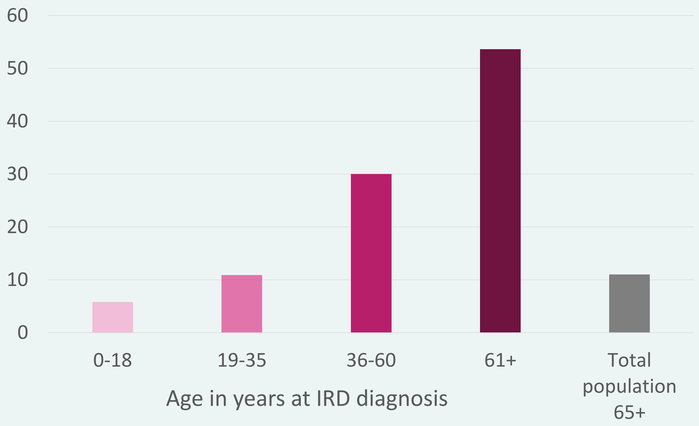
Alexandra Wennberg, Ph.D.[1], Henrike Häbel, Ph.D.[1], Ying Qu, Ph.D.[2], Nan Li, PhD[2], Marvin Sperling, M.D.[2], Adina L. Feldman, Ph.D.[1], Stefan Löfgren, M.D., Ph.D.[1]

1. Karolinska Institutet; 2. Janssen Global Commercial Strategy Organization

Aim: Evaluate resource utilization (e.g., homecare) to understand the impact of IRDs.

Conclusions: Homecare use was common among IRD patients and was independently associated with mortality. Older IRD patients and those diagnosed earlier had greater odds of homecare use. These findings suggest that IRD patients have a significant need for homecare, impacting the care system and individual and societal economy.

Percent of IRD Patients Using Homecare

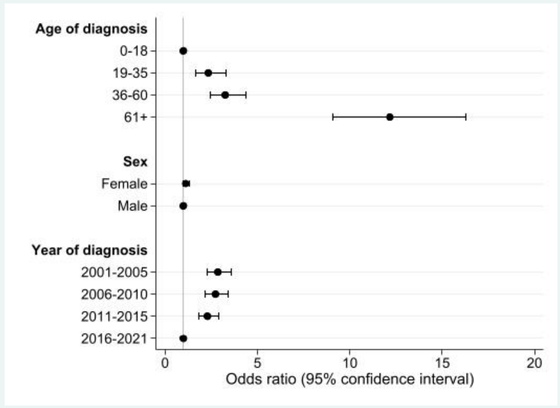


A total 18.8% (970/5164) used homecare. Patients who used homecare were older at diagnosis, a greater proportion were women, and had a longer disease duration. Compared to the total older Swedish population (≥65), 11% of whom used homecare, 39% of older IRD patients (≥61) used homecare.

Introduction: IRDs are a diverse group of progressive conditions that can lead to severe vision impairment and blindness. ~4.5 million people worldwide are IRD patients. They often need formal homecare, which is associated with high costs for patients and society.

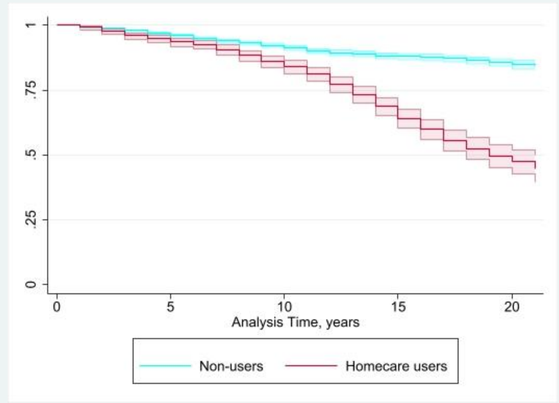
Methods: A longitudinal (2013-2021) cohort study in Swedish national register data. Multivariable logistic and Poisson regression models were used to compare homecare use among IRD patients.

Odds of Homecare Use Among IRD Patients



In logistic regression models, patients aged ≥61 at diagnosis (OR=12.17, 95% CI 9.09, 16.29) and those diagnosed earlier (2001—2005) (OR=2.87, 95% CI 2.31, 3.56) had higher odds of homecare use.

Kaplan-Meier Survival Estimates



In Poisson regression models, homecare use was associated with mortality, independent of age and sex (IRR=1.39, 95% CI 1.20, 1.61).

Future directions: Future analysis will compare IRD patients and matched comparison subjects. We will investigate the direct and indirect costs of homecare use in IRD and how this impacts families. We will also examine the relationship between comorbidities and homecare use, and how this may impact mortality rates.

This project is part of an ongoing collaboration between Karolinksa Institutet and Janssen Pharmaceutica NV. Please contact the lead author for more information:
Karolinska Institutet
Department of Clinical Neuroscience
Tomtebodavägen 18A
171 77 Stockholm Sweden
Alexandra.wennberg@ki.se

Karolinska Institutet