Interface management concepts in the health care for rare diseases in Germany: A mixed-methods study to develop best practice recommendations

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Patients and families affected by a rare disease are burdened in multiple ways and face specific challenges. It can take several years until patients receive the accurate diagnosis. Additionally, receiving appropriate health care might be difficult in the home area of patients due to the rarity of the diseases and specialized treatment centers. Intersectional communication and coordination are crucial to enable continuity of disease management.

BACKGROUND

The findings will provide a systematic assessment of the current state of interface management in the context of rare diseases in Germany. A structured assessment tool to evaluate the interface management will be developed. The tool will focus on processes regarding the access to centers for rare diseases and information transfer to and from other health care providers.

At the end of the study, consented best practice recommendations will allow health care institutions to improve their interface management. This results in an improved journey through the health care system for affected patients and their relatives.

OBJECTIVES

1) Systematic inventory and analysis of existing concepts and instruments regarding interface management of rare diseases
2) Development of recommendations for implementation of a cross-sectional best-practice model

EXPECTED RESULTS & RELEVANCE FOR CARE

The findings will provide a systematic assessment of the current state of interface management in the context of rare diseases in Germany. A structured assessment tool to evaluate the interface management will be developed. The tool will focus on processes regarding the access to centers for rare diseases and information transfer to and from other health care providers.

At the end of the study, consented best practice recommendations will allow health care institutions to improve their interface management. This results in an improved journey through the health care system for affected patients and their relatives.

Flowchart of the study phases

Phase I
- Start 06/2019
- Analyses of existing concepts of interface management
  - Literature research
  - Expert workshop and on-site visitations of centers for rare diseases
  - Development of an assessment tool for interface management
  - Telephone survey of centers for rare diseases and practitioners
  - Selection of concepts

Phase II
- Evaluation of selected interface management concepts
  - Interviews with practitioners
  - Survey of patients with rare diseases or parents/legal guardians
  - Interviews with patients with rare diseases or parents/legal guardians

Phase III
- Integration and aggregation of results from phase 1 and phase 2
- Expert workshop
- Finalisation of consented best practice recommendations
- End 05/2021

(1) referring and cooperating primary and specialized caregivers