

Recentering Caregivers: Real-Time Data-Driven Healthcare Visualizations

Data Driven health interfaces allow for real time visualization of multi-source data that can be used for the planning and decision making of health related matters. A possible use-case for such interfaces is the navigation within the health-care system by caregivers of children with neuropsychiatric disabilities.

Currently Patient Centered Care (PCC) model is in focus. The World Health Organisation (WHO, 2019) defined people-centred health care as "an approach to care that consciously adopts the perspectives of individuals, families, and communities, and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways" (p. 1). The definition reflects the importance of involving the patient and their family in planning and delivering care. One patient group is children and teenagers with neuropsychiatric disabilities, such as ADHD, autism or Tourette's syndrome. This patient group is referred to various health facilities, such as healthcare centres or youth clinics. The health facilities conduct several investigations, with some duplicated due to the health facilities being managed by disconnected health care providers. One problem caused by the variation in management and investigation duplication is low confidence in the care and patients interrupting their treatments.

Another problem is that caregivers need to be project managers and understand the organisational parts of the healthcare system and the steps in their children's treatment. Therefore, those caregivers could be helped via a data-driven interface, where they can find information in one place about the coming steps in their children's care. The steps could include information about future care, such as why, when, and how. Other information could be accessed to previous results from investigations. There are problems related to our proposed interface, like the children's privacy and access to their data. Our suggestion for future research is to dig deeper into this area and understand the hindrances to creating a data driven health interface containing information for caregivers of children with neuropsychiatric disabilities.

WHO. (2019). *World Health Organization guideline: recommendations on digital interventions for health system strengthening*. World Health Organization.