

Experiences of ambulatory Huntington's Disease patients with case management; a qualitative study

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Background

The complex and devastating nature of Huntington's Disease (HD) requires high quality care to reduce disruption of the patient system, prevent crisis situations and prevent early admission in a nursing home. Case management is a widely used and strongly promoted complex intervention for organizing and coordinating care at the level of the individual, with the aim of providing long-term community care. Atlant deploys case managers to support and coordinate care for outpatients with HD in their living environment. Experiences and beliefs of HD patients with case management and the implications of case managers' care, guidance and support for quality of life are not examined before.

Aim

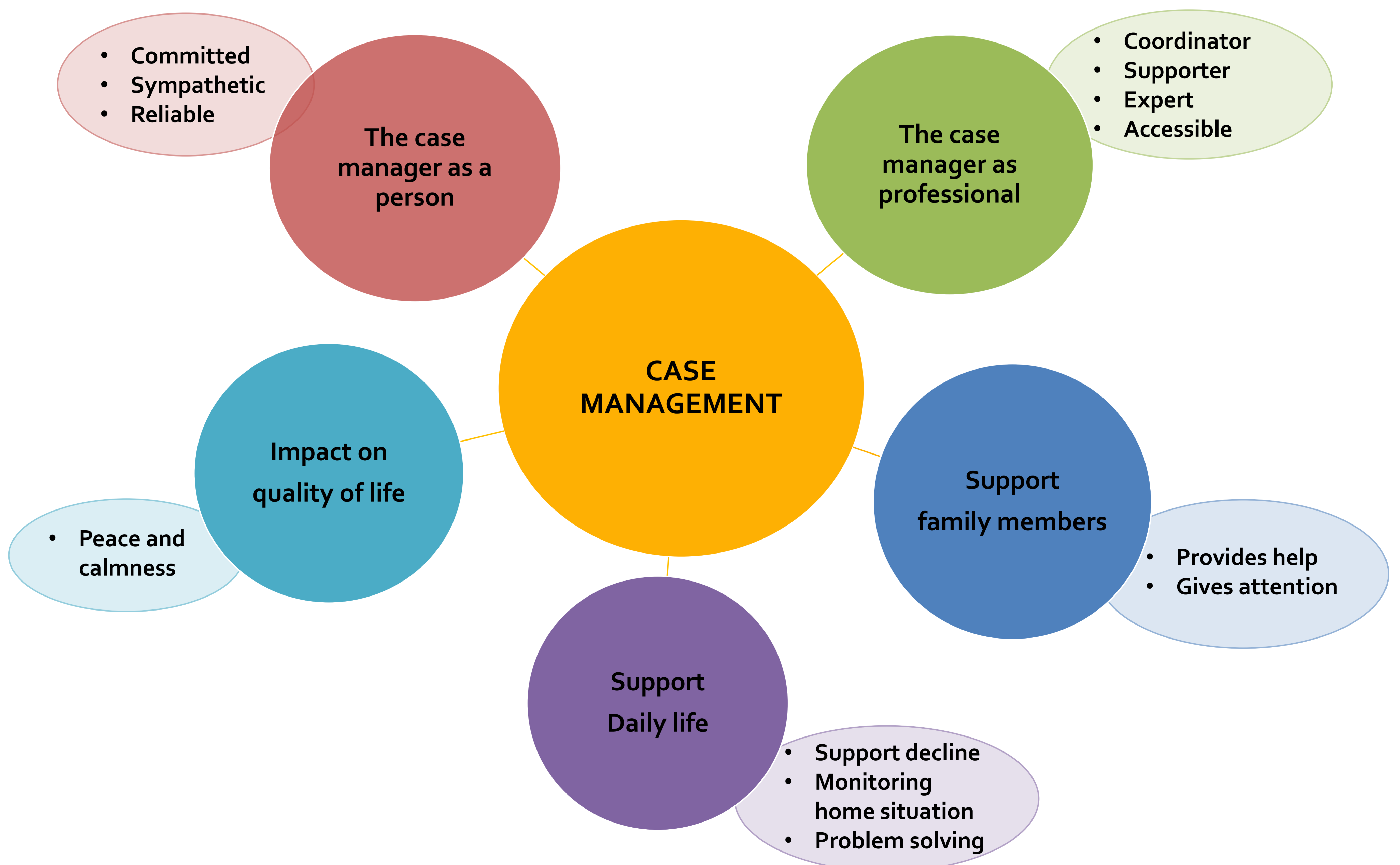
Insight in experiences of ambulatory HD patients with the care, guidance and support received from a case manager.

Methods

A qualitative design using semi-structured interviews to collect experiences and beliefs. Data were analyzed using Thematic Analysis.

Preliminary results

In total 14 HD patients from the outpatient department of Atlant participated during 2020-2021; 8 women and 6 men, between 30 and 75 years old. Analysis of the interviews revealed 5 themes, and 13 subthemes.



Preliminary conclusions

Case management was deemed positive by ambulatory HD patients. Expertise, accessibility, support and bond of trust from the case manager are experienced as very valuable.

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