Caregiver burden in growth hormone deficiency: a targeted review

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Background & Objectives

Growth hormone deficiency (GHD) is a medical condition characterized by inadequate production of growth hormone, leading to growth retardation and delays in maturation[1]. To address these challenges, daily hormone injections are often required as a primary treatment[2]. In recent years, there has been a growing recognition of the significant impact that chronic conditions can have not only on the patients themselves, but also on their caregivers, who play a vital role in providing support and managing treatment[3-5].

Given this increasing interest in understanding the broader implications of disease on those closest to the patient, this review aimed to identify literature assessing the burden experienced by caregivers of people with GHD.

Methods

To conduct the targeted literature review, PubMed and Google Scholar databases were utilized. The search strategy employed specific keywords related to GHD, including "growth hormone deficiency", "short stature", and "recombinant human growth hormone therapy". Additionally, the search terms "caregiver" and/or "carer" were incorporated to ensure the inclusion of relevant studies focusing on the burden experienced by caregivers.

Results

A total of seven research papers exploring the impact of GHD on caregivers across the US and Europe were identified. Methodologies included qualitative interviews (two studies)[1,3], quantitative surveys (four studies)[2,6-8], and a mixed-methods approach (one study)[4].

Five studies examined the burden of caregiving in terms of impact on daily life and activities. Several common themes emerged from these studies (see **Figure 1**), including challenges associated with travel, disruptions to social life, and the burden associated with the preparation, administration, and storage of hormone injections. One study found that caregivers of individuals receiving weekly treatments experienced a lower burden in terms of life interference compared to caregivers of individuals receiving daily treatments.

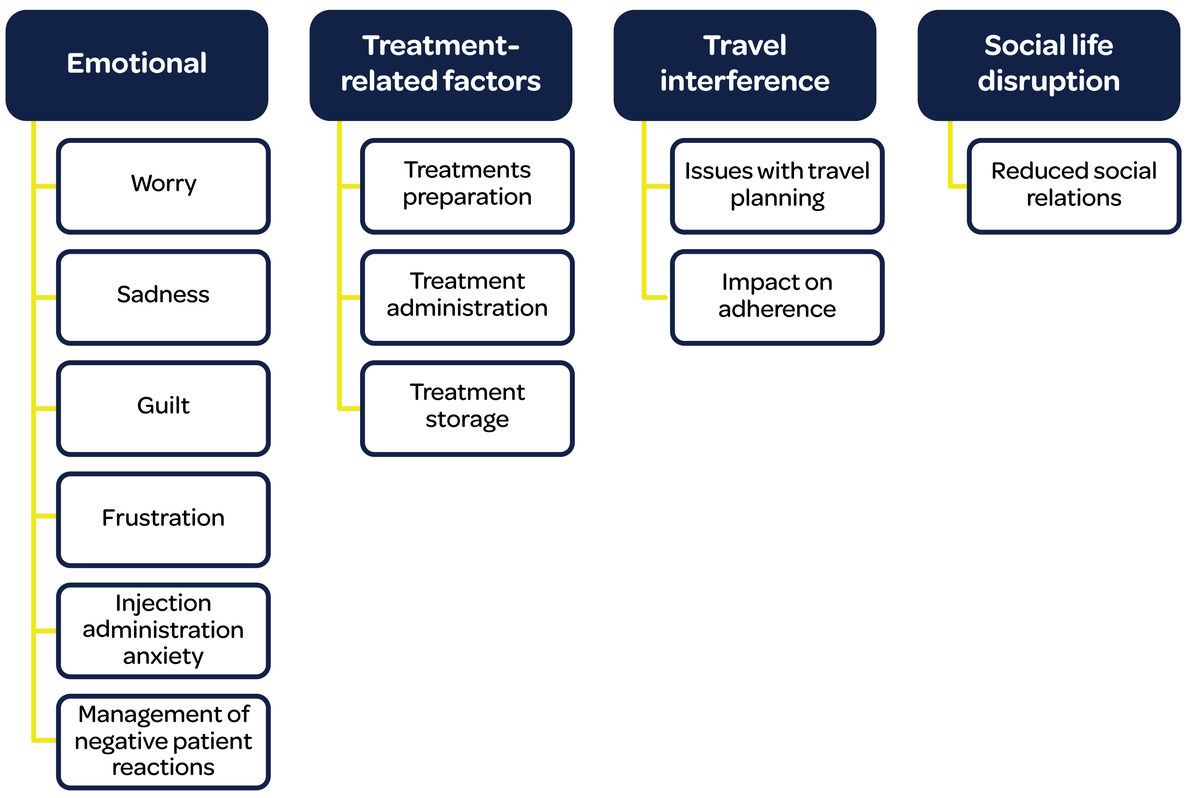

Figure 1: Key types of burden and challenges associated with caring for people with growth hormone deficiency (GHD)

An additional emergent theme, described in four studies, was the emotional impact of caregiving responsibilities, which extended to the challenges of managing negative reactions from patients and anxiety related to administering injections. The various types of emotional burden shown in **Figure 1** were associated with reduced mental wellbeing and self-efficacy among caregivers. One quantitative study associated higher caregiving stress with greater disease severity, which in turn impacted on overall quality of life.

Discussion & Conclusions

The findings from this review highlight the existing literature that describes the significant burdens experienced by caregivers of people with GHD. The identified studies consistently demonstrate that GHD not only impacts the daily lives and social activities of caregivers, but also that it has a notable effect on their emotional wellbeing.

The recognition of caregiver burden in the context of GHD is crucial for facilitating comprehensive healthcare decision-making. Inclusion of the caregiver perspective can ensure a more holistic understanding of the challenges faced by caregivers, including the impact of GHD and its treatment on their lives. Healthcare professionals, policy makers, and researchers can utilize these valuable insights into the multifaceted aspects of caregiver burden to develop more effective support strategies and interventions. Moreover, recognizing and addressing caregiver burden can contribute to improved patient outcomes, considering that caregivers play a pivotal role in the daily management of GHD and that their wellbeing can directly impact on their ability to provide adequate care and support.

It is important to acknowledge that the current body of research on caregiver burden in the context of GHD is relatively limited[5]. This observation highlights an opportunity for researchers to contribute to the field by expanding the existing knowledge base and generating more robust evidence on this topic.

References

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