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The Pediatric Growth Hormone Deficiency Patient Journey: Identifying Opportunities For Digital Health Interventions

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Abstract. Pediatric growth hormone deficiency (PGHD) is a chronic condition where the pituitary gland fails to produce sufficient growth hormone, leading to delayed growth and developmental challenges. Patient journey maps can provide insight into pain points and potential opportunities for new or improved interventions to enhance care. However, a patient journey map does not yet exist for PGHD. Secondary data analysis was performed on interviews and focus groups from five cohorts in Sweden, the United Kingdom, Luxembourg, France, and The Netherlands. Participants included 62 patients and caregivers who used a prototype digital health solution, which was used to guide discussions. Grounded theory was used to analyze the data, resulting in a patient journey map comprising six stages: awareness, diagnosis, treatment planning, treatment initiation, treatment maintenance and transition. This provides the first detailed PGHD patient journey map, revealing emotional sensitivities and challenges at each stage, and suggesting areas for targeted interventions to improve adherence and long-term outcomes.

Keywords. Digital health; growth hormone deficiency; patient journey.

1. Introduction

Pediatric growth hormone deficiency (PGHD) is a chronic condition in which the pituitary gland does not produce enough growth hormone (GH). Children with PGHD have delayed growth, shorter stature, slower development, decreased muscle mass, and weaker bones, and are at a higher risk of developing obesity [1-3]. Treatment for PGHD

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typically involves regular injections of recombinant human GH (r-hGH), which promotes growth and development in affected children [4]. Children are often diagnosed and commence therapy at an early age and, therefore, the active involvement of caregivers at the beginning of the treatment journey is essential. As GH treatment is most successful when taken from early childhood to adolescence [4], there is an opportunity to optimize habit formation which is strongly correlated with medication adherence [5]. As PGHD treatment burden is high, a patient-centric approach that emphasizes self-management may be required [6,7].

Treatment can be facilitated by digital health tools, combining state-of-the-art digital technology and analytics to support self-management [8]. Digital health tools have been successfully used to support self-management in other chronic conditions, and there has been a recent increase in interest regarding their use for PGHD. However, to create meaningful user experiences, it is crucial to accurately represent the needs of the target users, so that solutions are widely adopted and used consistently.

A patient journey map is a visual representation of a patient's lived experience of their chronic condition, including physical, digital and emotional experiences, representing an individual's experiences while using a product or service [9]. Mapping a patient's journey provides insight on pain points and potential opportunities for new or improved interventions to enhance their care [9-11]. However, a patient journey map for PGHD has not previously been created. The present analysis was therefore designed to map the journey of patients with PGHD and identify opportunities for current and novel digital health interventions in different cultural and international contexts.

2. Methods

The journey mapping drew on secondary data analysis of transcripts and synthesized reports from five cohorts who participated in interviews, focus groups, and prototype testing of a digital health solution. The goal was to understand their experiences with PGHD and assess their perceptions of the solution's usefulness, usability, and overall design. Cohorts comprised patients receiving GH therapy and their caregivers (n=62) using the prototype of a digital health solution in Sweden, the United Kingdom, Luxembourg, France, and the Netherlands between 2016 and 2021. Participants were recruited through multiple channels, including third party recruitment agencies, and received a nominal fee for their participation.

Data analysis was conducted in an iterative process using grounded theory [12]. The journey mapping involved organizing the observations chronologically, capturing the detailed flow of activities, perceptions, and emotions that patients and their families experience as they navigate the diagnosis and treatment of their condition.

3. Results

Experiences and views of patients with PGHD and their caregivers were identified and categorized into a timeline that included six stages: *awareness*, *diagnosis*, *treatment planning*, *treatment initiation*, *treatment maintenance* and *transition*. For each stage relevant concerns and emotions were identified. These included: 1) pre-diagnosis concerns and uncertainty; 2) difficulties initiating contact with HCPs due to insufficient communicative support; 3) increasing confusion and concern about the future;

4) concerns about whether self-management is being performed correctly; 5) the need to deal with inconvenient and hurtful routines; 6) uncertainty about the impact and role of adherence; 7) long-term therapy fatigue; and 8) difficulties of change to self-administration during adolescence.

Participants saw early training and treatment onboarding as key factors to establish a treatment routine and helping families deal with injection pain. Early access to patient support groups and building connections with other families who had gone through or were currently going through a similar situation were seen as helpful in understanding the future patient journey. Long-term treatment fatigue was a common concern among participants, especially as patients approached adolescence. The role of HCPs in clarifying expectations and upcoming changes and supporting the transfer of ownership to the teenager were highlighted, as were expectations for HCPs and caregivers to support new routines for ongoing care and wellbeing during the transition period.

Digital health applications were seen as a potential channel to improve the patient–HCP relationship and increase communication with HCPs. Digital health solutions were also seen as useful to manage expectations about likely growth outcomes. Gamification and customizable features as part of a structured approach were considered essential.

3.1. Patient journey

Through analysis of the data, a draft PGHD patient journey was created (a low definition version can be found in Figure 1, for a more detailed version see http://medpub-poster.merckgroup.com/Figure5.jpg).

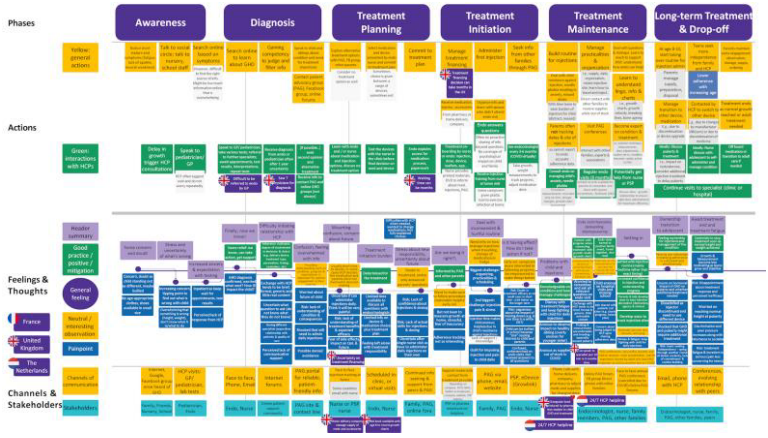

Figure 1. PGHD patient journey map.

4. Discussion

Our analysis provides the first detailed description of the patient journey for individuals receiving r-hGH therapy for PGHD from a caregiver and patient perspective. The patient journey map generated from this work identifies the emotional sensitivities and challenges associated with PGHD and its treatment, adding to the findings of previous studies that have demonstrated the impact of PGHD (and its treatment) on the emotional and social aspects of patients' daily lives [13,14]. The patient journey map provides areas

of focus that could support a solutions-based approach to improve adherence to therapy and enhance long-term treatment. In particular, participants noted that interventions at an earlier stage of the patient journey were deemed important in establishing the treatment and helping to understand the future patient journey. Given that children with PGHD who start treatment at a younger age have improved growth outcomes [15, 16], a focus on the earlier stage of the journey could improve overall patient and caregiver satisfaction and commitment to long term GH therapy, particularly as long-term treatment fatigue was a common concern among participants, especially when patients approached adolescence.

There has been an acceleration in patient journey mapping research, with 76.5% of articles published since 2015 [17]. These journeys can help visualize the interactions between individuals and a product or service (or, in this case, a digital health application) over time across different channels [10]. Journey mapping studies are conducted for numerous reasons, including to inform health service redesign, understand how a patient moves through the health system, identify delays in diagnosis and treatment, evaluate continuity of care, and to compare patient experiences with practice guidelines [17]. By conducting journey mapping studies, patient-centric healthcare models can be generated, resulting in improved care and better patient outcomes. Other conditions that have had patient journeys mapped include melanoma, opioid use disorder-associated endocarditis, squamous neoplasia, peripheral neuropathy and acne. Patient journey studies have also been conducted for transgender individuals, to improve their interactions with healthcare providers, and for caregivers of older people to understand how healthcare is accessed. It is important to note that patient journeys should consider both cultural context and national healthcare systems, as a map generated from patient experiences in one region may not reflect the experiences of a patient from another.

Generating a map for PGHD allowed us to understand how patients learn about their diagnosis, what issues are faced during their treatment journey, and when digital health interventions can potentially be used. When an HCP can visualize these issues (e.g. lack of confidence about injection, fear of side effects), solutions can be provided that potentially improve patient adherence to medication and therefore clinical outcomes.

Limitations. Qualitative research is often subjective and can be influenced by the research team's personal biases and perspectives, which can affect the interpretation of the data. Additionally, the study relied heavily on the input of participants, who may not always provide fully accurate responses due to social desirability bias or other factors. As the patient journey provides a simplified view of patient experiences, our proposed journey may not capture the full complexity and context of the interactions a patient with PGHD has along the healthcare pathway.

5. Conclusions

The proposed patient journey for PGHD offers new insights into patients receiving r-hGH therapy and the potential opportunities for effective digital health interventions that may improve both clinical- and patient-reported outcomes. Participants identified the concerns and emotions experienced at each stage of the patient journey and saw value in a prototype digital health application to support the management of PGHD, especially during the treatment onboarding process. Future studies assessing the impact of digital health solutions on growth outcomes will provide valuable evidence to further incorporate digital health technologies into the patient journey.

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