

# Parent Experiences Surrounding the Diagnosis of Their Child with a Chronic Health Condition: A Parent Navigation Model and Practice Implications

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DOI: [10.5014/ajot.2024.78S2-PO93](https://doi.org/10.5014/ajot.2024.78S2-PO93)

Date presented: March 22, 24

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**PURPOSE:** When a child is diagnosed with a chronic health condition, parents face immediate, unforeseen challenges. Ambiguities between parental self-care and child-care are interwoven with grief processes (McKnight, 2015). Identifying complex parent experiences can inform often child-centric care systems that potentially overlook parental needs. Therefore, this study's purpose was to examine parent experiences during and after receiving their child's chronic health diagnosis.

**DESIGN:** Researchers used a qualitative grounded-theory approach. Researchers recruited participants via email using convenience and snowball sampling. English-speaking parents with a child with a chronic health condition ages birth-17 years were included. The study had no exclusion criteria.

**METHOD:** Researchers collected data via a semi-structured interview with 16 parents. Interviews were audiorecorded and transcribed verbatim. Two researchers analyzed data first by independently coding transcripts and then meeting together to reach consensus. Researchers merged codes into categories, then into final themes that reflected parent experiences. Researchers generated a model of parent navigation based on the themes.

**RESULTS:** Parents navigated their child's diagnosis in a dynamic process marked by cyclic phases of unknowing, grief, fear, and guilt. Time and experience mediated these phases toward positivity, which transcended everyday struggles.

**CONCLUSION:** Parents of children with chronic health conditions navigate their child's diagnosis via a fluid journey of emotion-based phases mediated by time and experience.

**IMPACT:** This study examined parent perspectives on a sensitive yet impactful therapy topic that inherently impacts traditionally child-centric occupational therapy services. Findings provide preliminary evidence supporting practitioners to elucidate and normalize complex parent experiences within therapeutic interactions to optimize therapy processes.

## References

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