

Life with a shunt - Exploring the experience of parents of hydrocephalic children with a CSF-Shunt - a qualitative study

Anne Modwen Ehle | Conference Presentation | January 2021

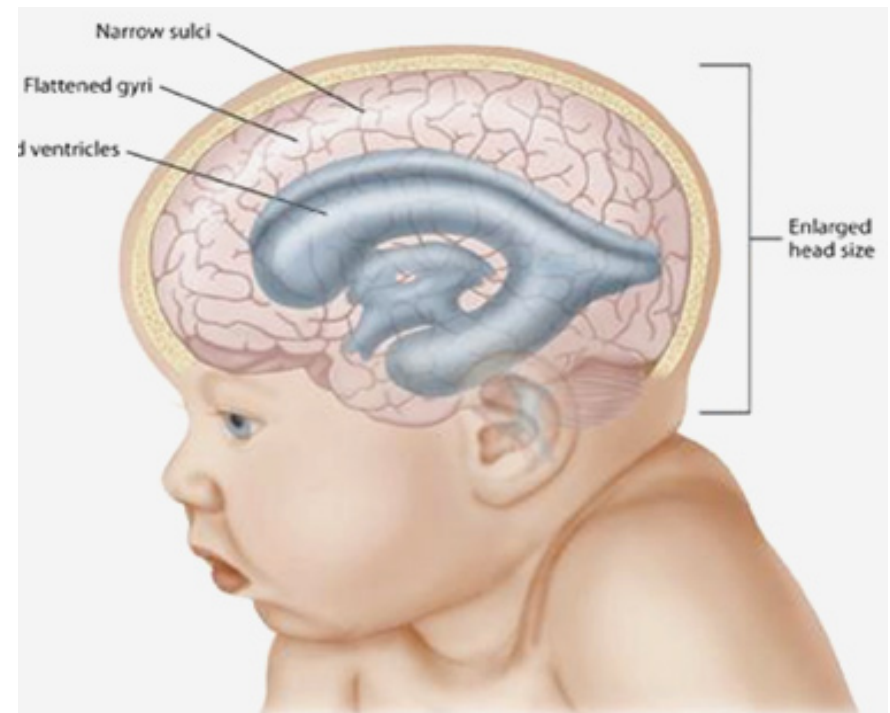
# Contents

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- Background
  - Hydrocephalus
  - Shunt
- Aims and Evaluation
- Methodology, Analysis and Interview Setting
- Results and Key Quotes
- Conclusion and Discussion
- Acknowledgements

## Background: What is Hydrocephalus?

- Accumulation of excess CSF in ventricular system, rising ICP
- Aetiology
- Burden: 80-110 / 100.000 l.b.
- Symptoms



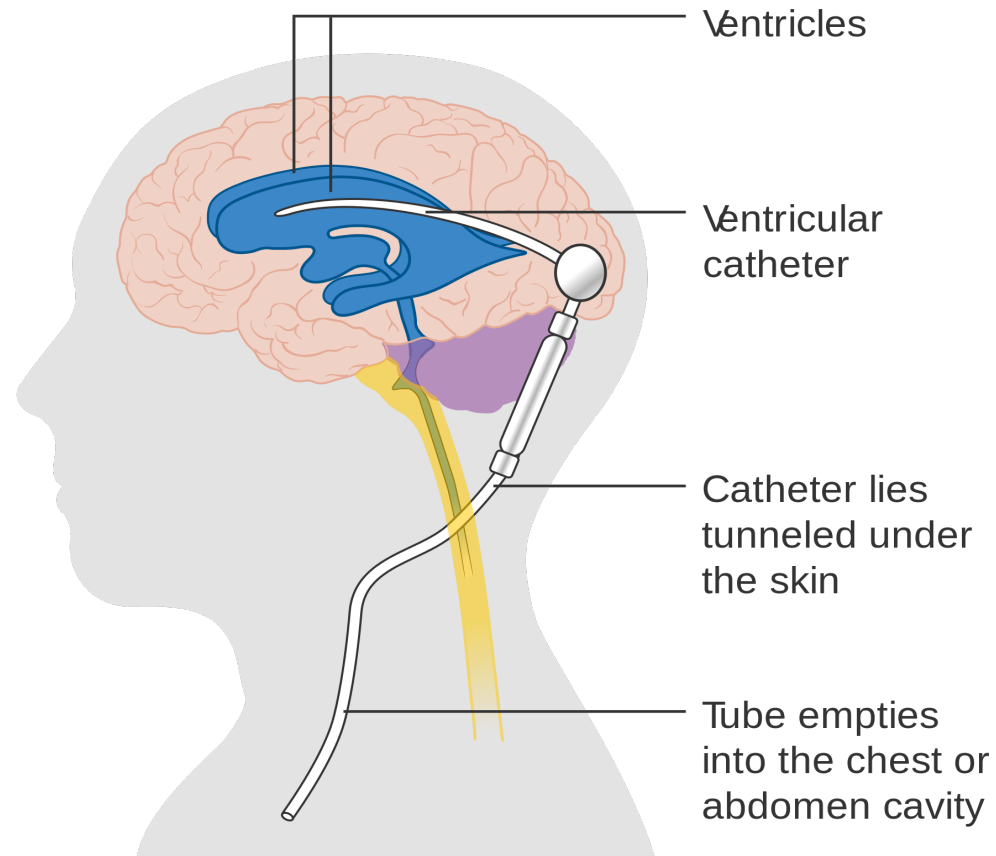
Picture 1: Child with Hydrocephalus <sup>1</sup>

# Background: Shunt

- Surgical implantation
- Indication
- Risks



Picture 2: Shunt device <sup>2</sup>



Picture 3: Shunt device explanation <sup>3</sup>

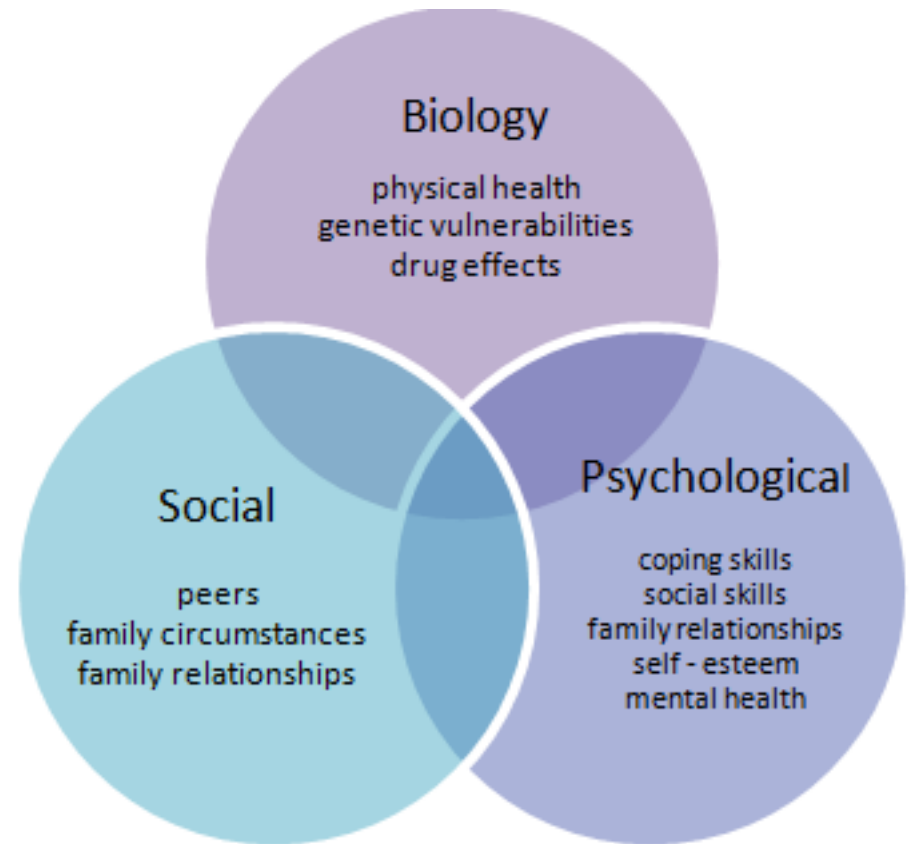
# Aims and Evaluation

## ■ Aim

- Find areas affected in daily lives
- Hear parents' worries
- Understand shunt patients more holistically

## ■ Evaluation

- Improve care and support
- Recognise problems

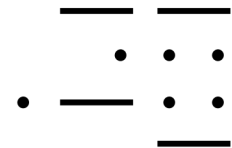
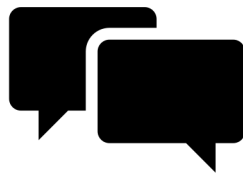


Picture 4: Bio Psycho Social Model <sup>4</sup>

# Methodology and Analysis

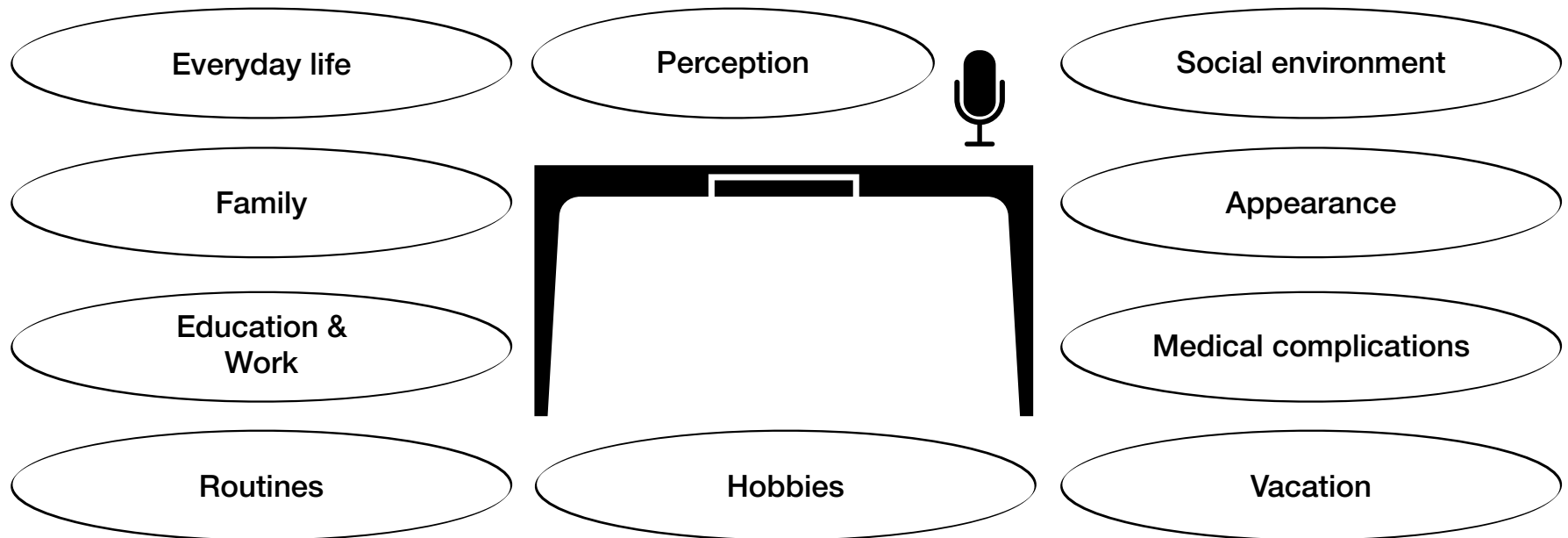
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- Contact families living with a child having a shunt
- Answers within inclusion period, appointments
- Semistructured interviews using guideline 30-60 min
- Transcription
- Coding using themes and analysis



# Interview setting

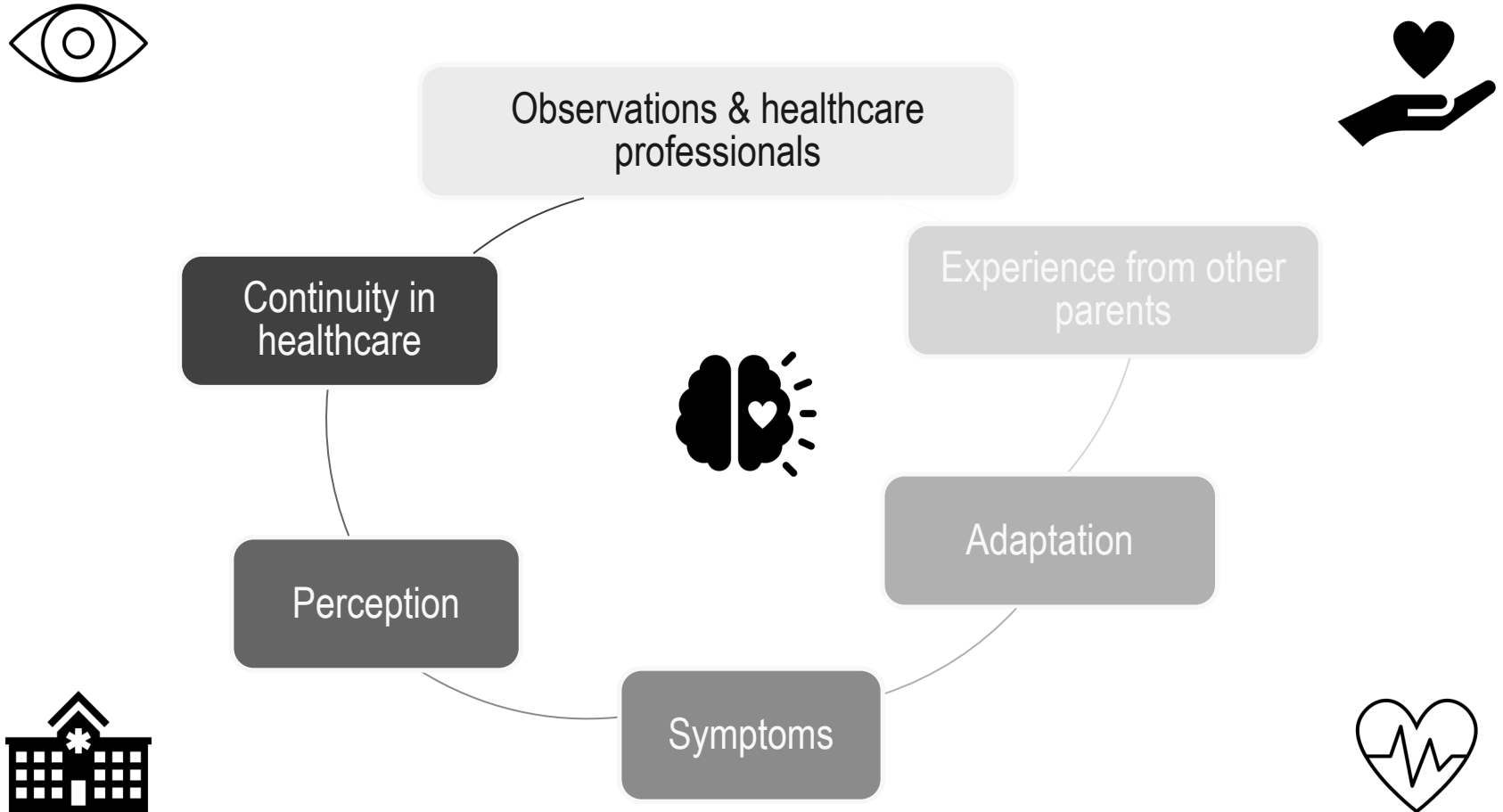
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Average duration: 1h

Total of 17 interviews

# Results



## Key- Quotes

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- ‘I barely think about it. It would take a lot for me to think the shunt is not functioning well. I wouldn’t take it out if I could. Why break something that is not broken?’ \*(15)
- ‘I can compare my worries in the past with them right now: Back then I felt like the hospital was our home. We were here at least every other day and now we actually settled in at our actual home. The disease is not as notable anymore. Right now we actually live and the shunt exists.” \*(08)

\*translated from german interviews

# Results: Conclusion

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- Subjective answers, personal and constant care helpful
- Trust in and from healthcare professionals

## Conclusion

- How can we help?
- What should change?
- What is important?



Picture 5: Patient interaction <sup>5</sup>

# Discussion

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## ■ Strengths:

- Parents' accounts and experiences, open questions
- Multiple perspectives from different family situations
- Guideline created using professional's experience

## ■ Limitations:

- Qualitative research: subjective, careful when generalising, especially regarding other healthcare systems
- Children's underlying and additional diseases (ethics)
- Lack of cohort demographics

# Acknowledgements

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I'd like to also thank:

Dr Manuela Pötschke

David Köditz



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# THANK YOU FOR LISTENING.

## ANY QUESTIONS?



## REFERENCES

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Picture 1: <http://www.kinderneurochirurgie-leipzig.de/schwerpunkte/hydrocephalus/hydrocephalus-therapie-mit-shuntsystemen/>

Picture 2: <http://www.kinderneurochirurgie-leipzig.de/schwerpunkte/hydrocephalus/hydrocephalus-therapie-mit-shuntsystemen/>

Picture 3: [https://en.wikipedia.org/wiki/Cerebral\\_shunt](https://en.wikipedia.org/wiki/Cerebral_shunt)

Picture 4: [https://en.wikipedia.org/wiki/Biopsychosocial\\_model](https://en.wikipedia.org/wiki/Biopsychosocial_model)

Picture 5: <https://www.utoronto.ca/news/female-doctors-better-health-care-experience-gender-pay-gap-discrimination-and-depression-u-t>