

Exploring Life with a Shunt

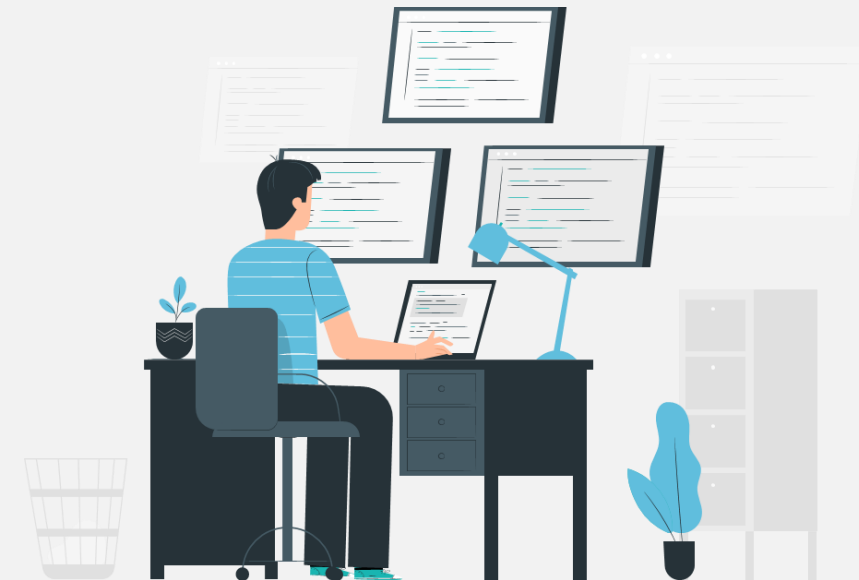
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Qualitative Interviews with Hydrocephalic Patients with a CSF - Shunt

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Professional Designs via TeePublic
[<https://tinyurl.com/ycvfon4b>]



Content

- 🧠 Background
- 🧠 Methods
- 🧠 Selected Findings
- 🧠 Discussion
- 🧠 Summary
- 🧠 Acknowledgements



Background – Hydrocephalus & QoL

Abnormal quantities of cerebrospinal fluid (CSF) in the ventricles

No universal definition

Different types



Many symptoms



Shunt treatment



Subjective

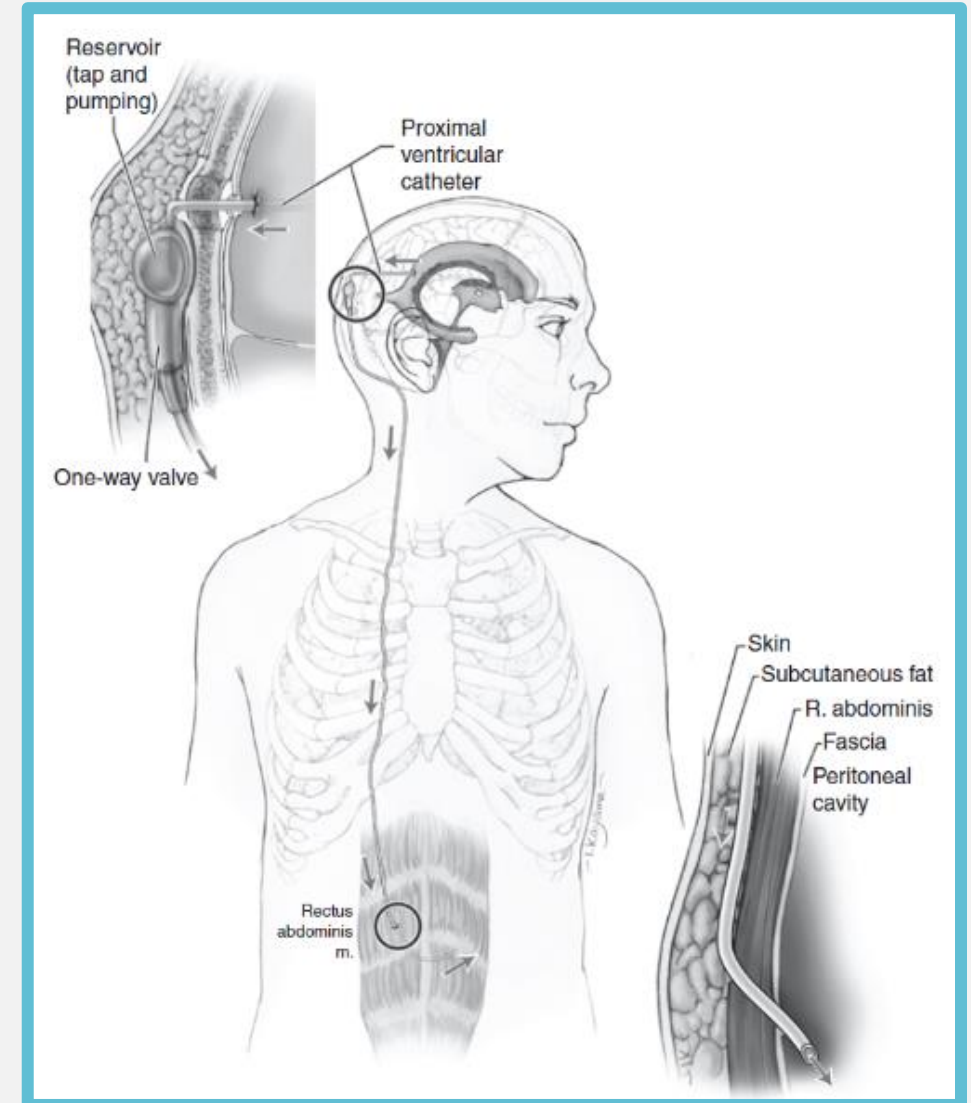


Dynamic



Background – Shunts

- 🧠 Diverts CSF
- 🧠 Comes with high revision rates and **complications**
- 🧠 Improves symptoms and thus **QoL?**



Rigamonti D. (ed.), Adult Hydrocephalus

Background – Research Gap

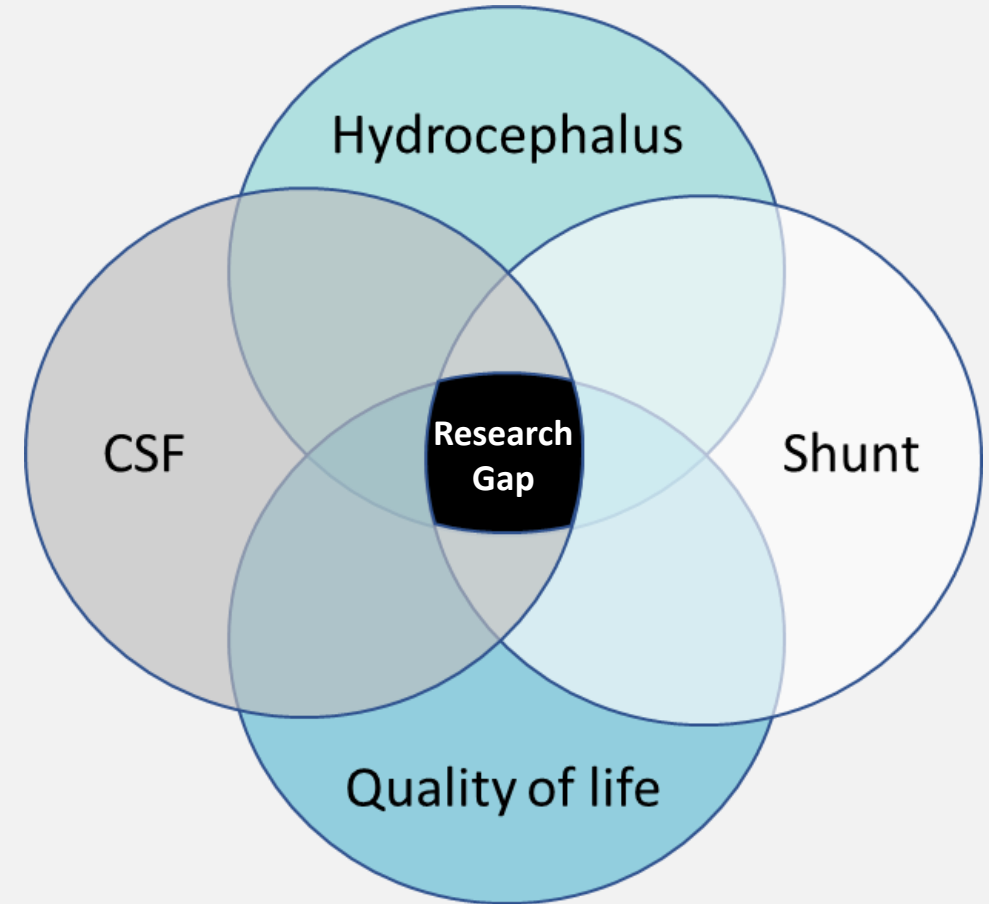
- 🧠 Not much QoL **research** concerning hydrocephalus
- 🧠 **Disease - specific** tools more effective

1

How does life change due to a shunt?

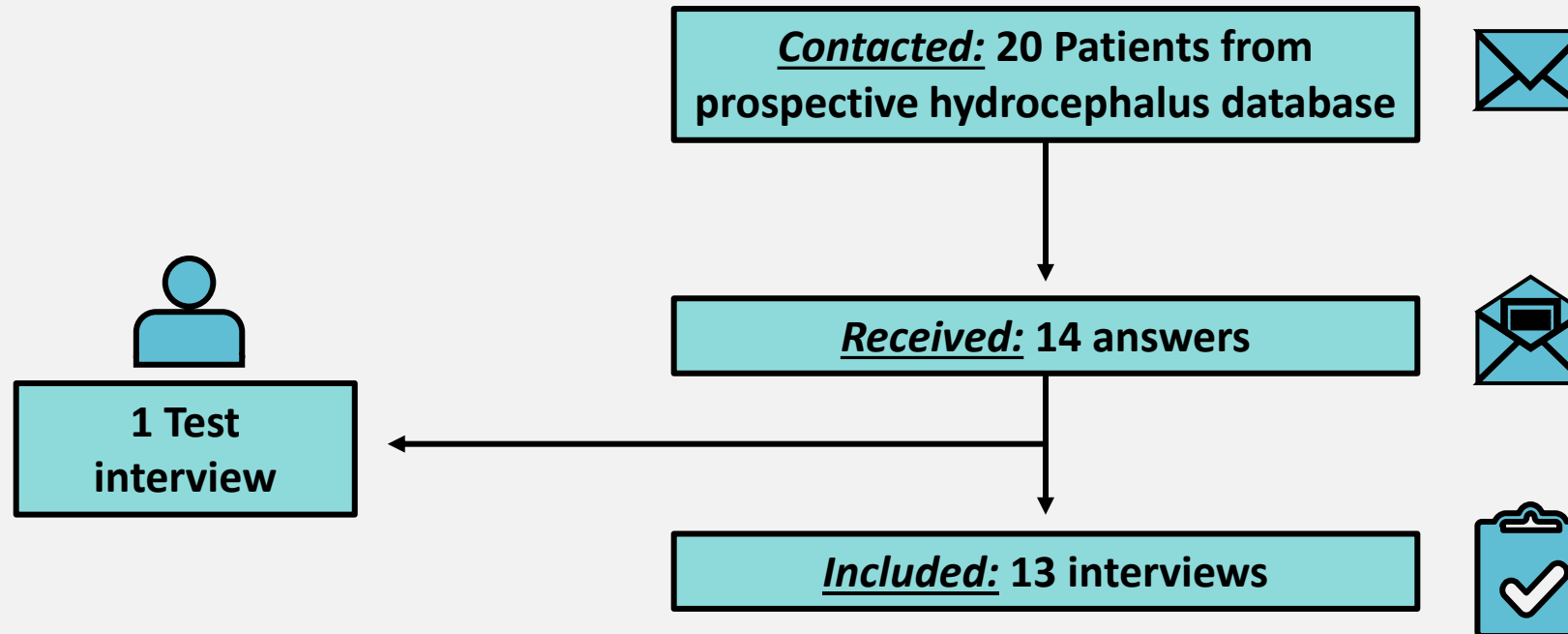
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Foundation for QoL questionnaire



Methods – Patient Flow Chart

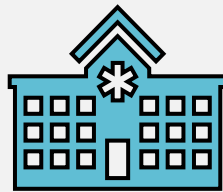
 10-20



ERGO: 55778



Methods – Interviews



Shunt surgery



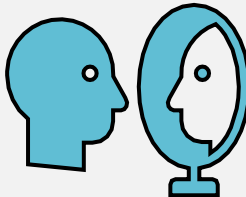
Shunt



Health



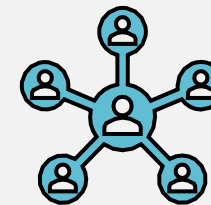
Occupation










*Self –
perception*



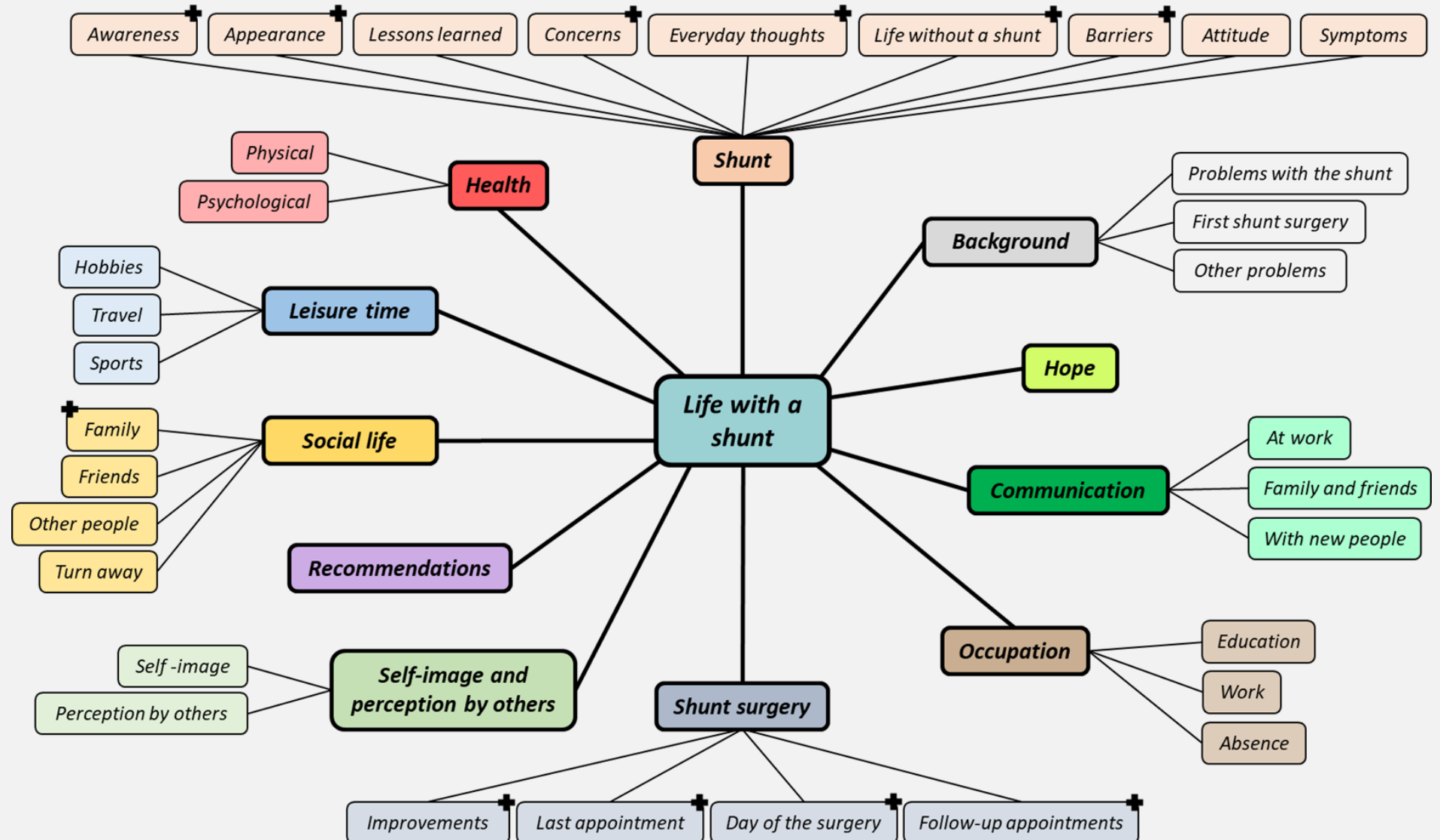
Leisure time



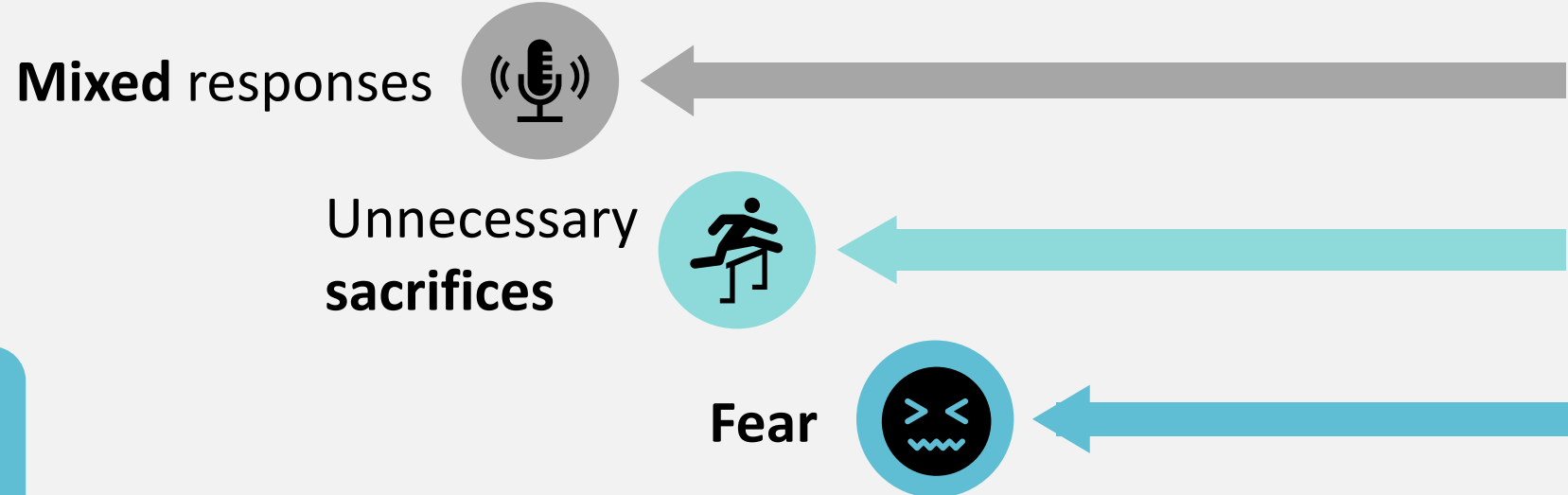
Social life

 <p>Self-image and perception</p>	<p>How did you perceive yourself before the shunt surgery?</p> <p>How do you think have others perceived you before the shunt surgery?</p> <p>How do you perceive yourself now after the shunt surgery?</p> <p>Does the impact of the shunt on your appearance bother you?</p> <p>Do you think other people notice the shunt immediately?</p> <p>How do you think do others perceive you now after the shunt surgery?</p>
 <p>Leisure time</p>	<p>What did you do during your leisure time before the shunt surgery?</p> <p>Did you enjoy doing sports before your shunt surgery? If yes, what sort of sports?</p> <p>What do you do now during your leisure time after the shunt surgery?</p> <p>Is there any kind of sports or hobbies now which you did not do before the shunt surgery?</p> <p>Has your holiday planning changed due to the shunt?</p>
 <p>Social life</p>	<p>Would you describe yourself as a person who socialized a lot before the shunt surgery?</p> <p>How was your family situation before the shunt surgery?</p> <p>Have you noticed that relationship to people in your close environment did change after the shunt surgery?</p>
 <p>Occupation</p>	<p>What was your occupation before the shunt surgery?</p> <p>Has your work routine changed due to the shunt?</p>
 <p>Health</p>	<p>How was your health before the shunt surgery?</p> <p>→ How did you feel?</p> <p>How is your health now after the shunt surgery?</p>
 <p>Shunt surgery</p>	<p>If you visualise the day of the shunt surgery now, how did you feel?</p> <p>You had some briefings and debriefings around your shunt surgery, how did you experience them?</p> <p>→ Is there something you would improve the next time?</p> <p>If you visualise the last appointment because of the shunt now, how did you feel?</p>
 <p>Shunt</p>	<p>Do you think of your shunt during a normal day a lot?</p> <p>→ Which moments specifically?</p> <p>Can you feel the shunt at the moment and in general?</p> <p>Do you have concerns that something could go wrong in regard to the shunt?</p> <p>→ If yes, which moments specifically?</p> <p>How would your life look like if you did not decide to have the shunt surgery?</p>

Findings – Overview



Findings – Barriers & Concerns



"I fear that it [the shunt] bursts or something else goes wrong ..." (Interview 13)



Findings – Thoughts & Improvements

Do not think a lot about shunt



Symptom-related thoughts



No time




Communication




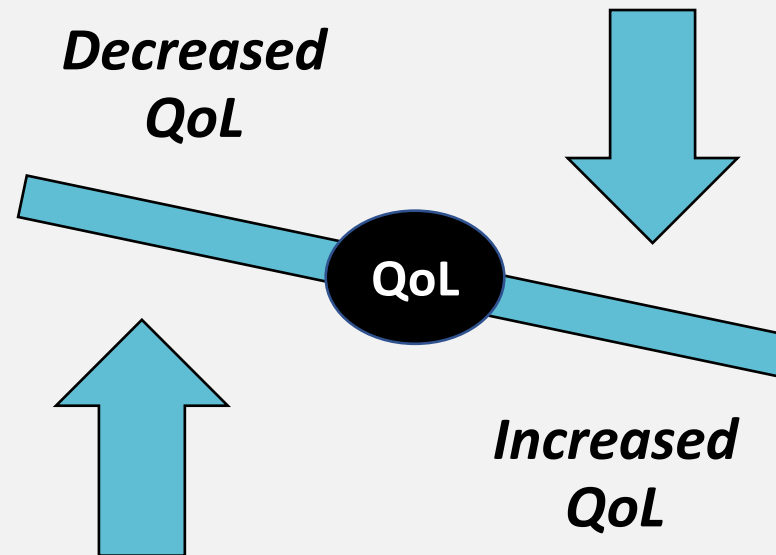
"Personally, I think that doctors do not talk a lot about the whole thing." (Interview 12)



Discussion



- 🧠 Communication
- 🧠 Anxiety
- 🧠 What can be attributed to my shunt?
- 🧠 What can I do with my shunt?



- 🧠 Live more consciously
- 🧠 More positive mindset
- 🧠 Gratitude

1

How does life change due to a shunt?

Summary

- 🧠 **First study** with this setting
- 🧠 **Plenty of topics** which affect QoL
- 🧠 **Mixed responses**
- 🧠 **Need for information** and **guidance**



Follow-up study of larger scale in the future

2

Foundation for QoL questionnaire



Acknowledgements



Dr Stefanie Kästner

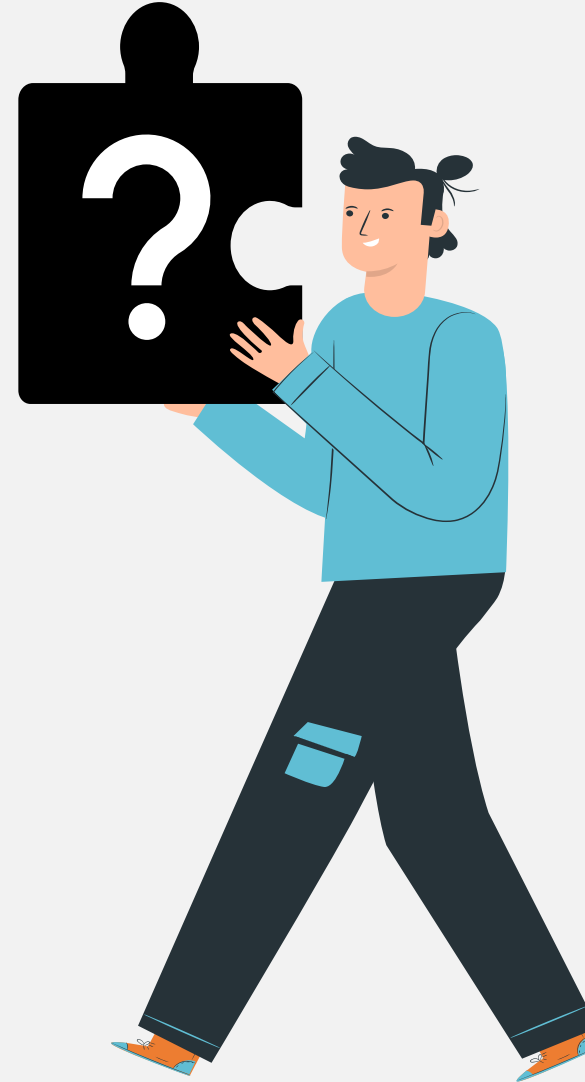


Dr Manuela Pötschke



Participants

Questions



Background – Quality of Life

Survival or reduction of symptoms



No universal definition or consensus!

Dynamic concept



Highly subjective



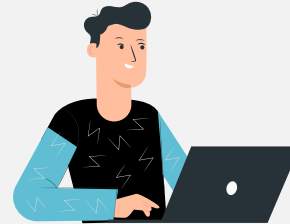
Different measures



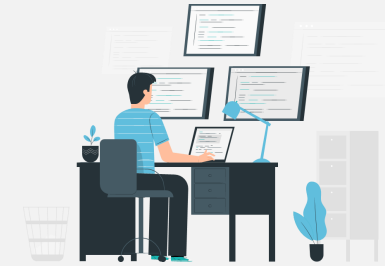
Methods – The road so far...



Interviews



Analysis



Interview
Guide

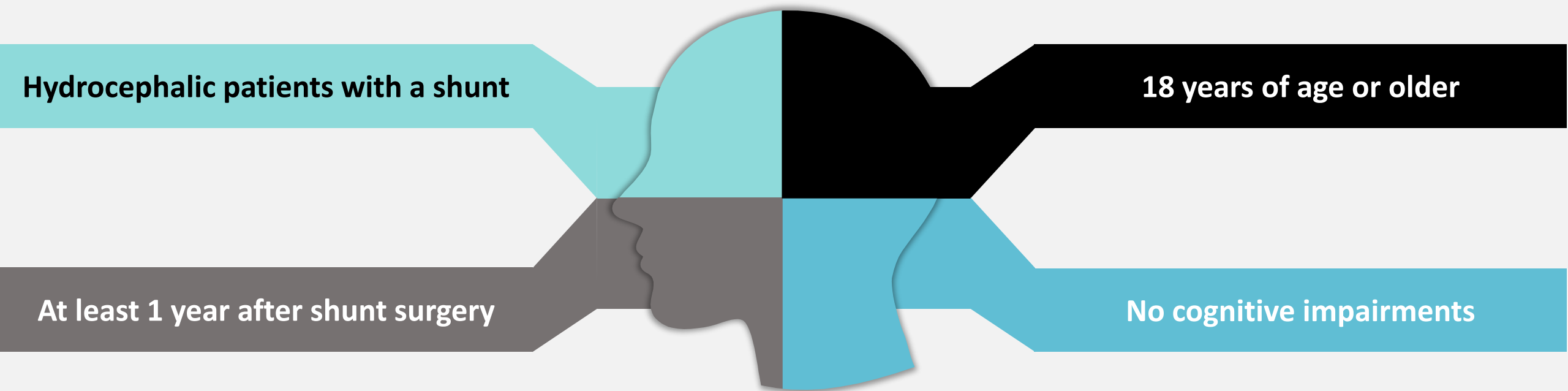


Transcription



Fine-tuning

Methods – Inclusion criteria



↓ **BIAS:** Stationary situated patients

Limitations

- 🧠 Transferability – Single institution
- 🧠 Selection bias – Negative attitude towards the shunt, participation
- 🧠 Reporting bias – Affect current treatment
- 🧠 QoL highly complex – Multiple health conditions

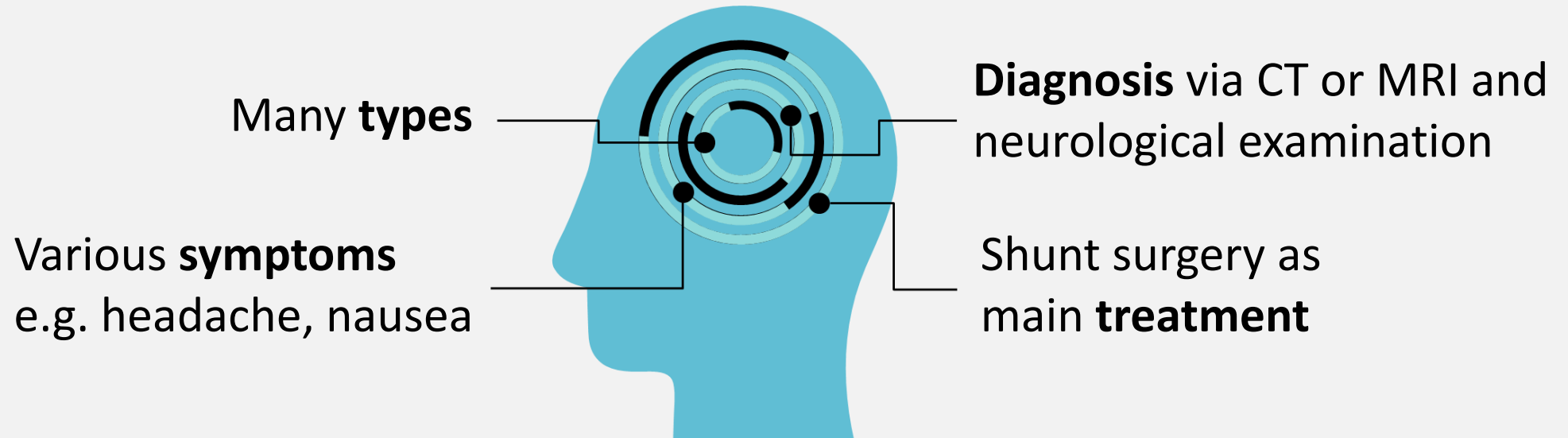
Hydrocephalus Facts – 1 (Incidence and prevalence)

- 🧠 Incidence up to 300 per 100 000 in the UK depending on region, age group and aetiology
- 🧠 Prevalence in US approximately 1 million
- 🧠 Incidence of hydrocephalus decreases with age
- 🧠 Incidence similar in Europe
- 🧠 500-700 newborns each year in Germany
- 🧠 7000 shunt surgeries (not revision) per year in Germany
- 🧠 Prevalence 58 per 100 000 in Germany

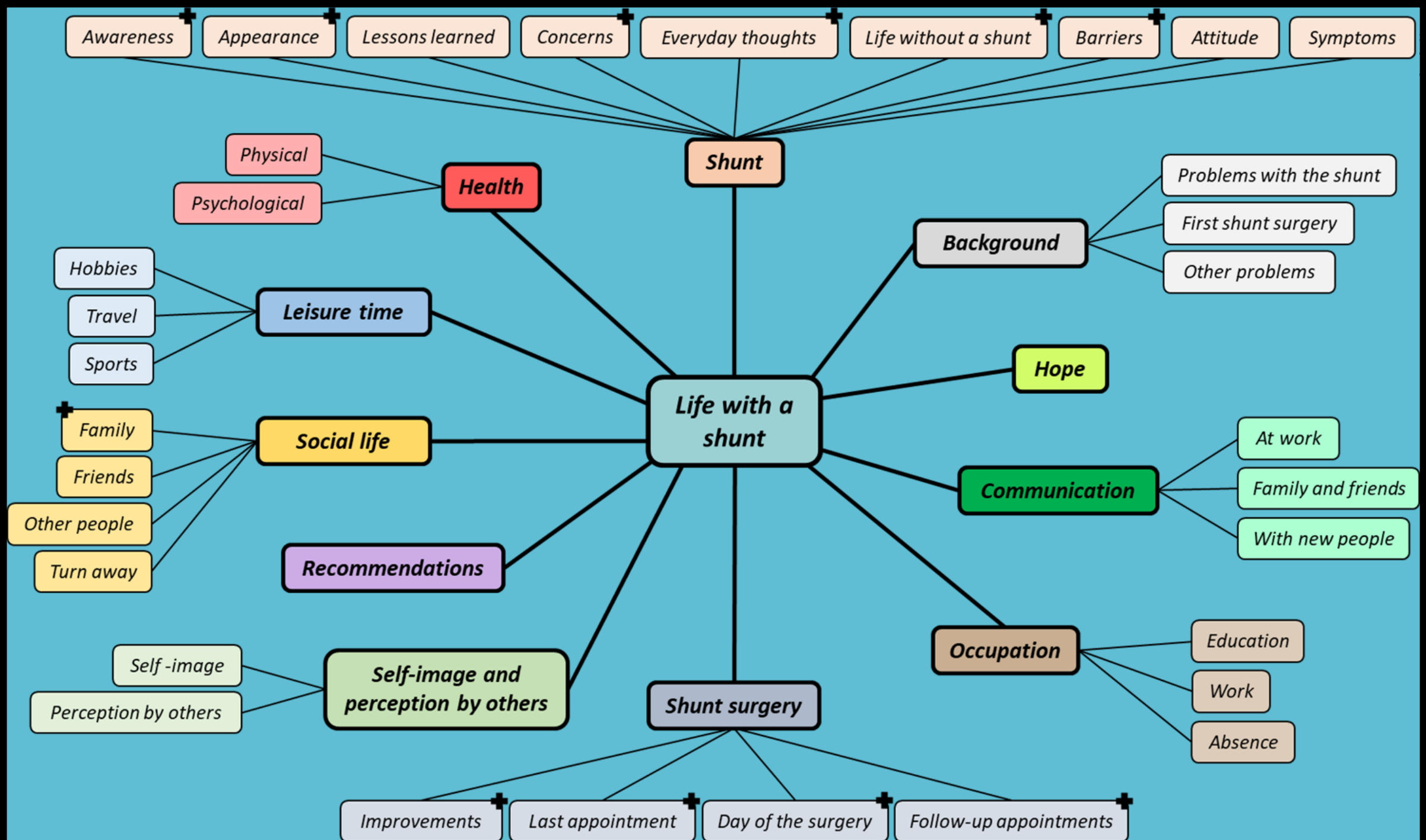
Hydrocephalus Facts – 2 (Complications)

- 🧠 Most common complications are shunt obstruction (15.9%) and catheter malposition (7.1%)
- 🧠 20% revision surgery within first year in UK
- 🧠 Shunt failure rates vary and can be as high as 45% in the first year after surgery
- 🧠 1930s shunt introduced
- 🧠 Hydrocephalus cases for 2021 (prognosis) = 12428

Background – Hydrocephalus



Abnormal quantities of cerebrospinal fluid (CSF) in the ventricles



- Use literal transcription
- Keep grammar even if it includes mistakes
- Keep duplications of words
- Use punctuation for readability
- Interviewer = “I”
- Participant = “P”
- Caretaker = “C”
- Add line numbers for referencing
- New paragraph for each interview participant
- Present emotional, nonverbal expressions such as laughter in brackets
- Rewrite dialects
- Ignore stuttering and unfinished words
- Mark clauses and unfinished sentences with a “/”
- Mark breaks longer than 3 seconds with “(...)”
- Mark incomprehensible words with “(unv.)”

61157 words

Transcription guide

	Other People		Participants describe the influence of the shunt on other people	<i>P: "I regularly go to the hairdresser, but my current hairdresser is sick ... and he asked, what is this? And I say, I have a shunt and then he said ok we have to be careful here ..." (Interview 13)</i>
	Turn away		Participants describe how people turn away from them because of the shunt	<i>P: "... and later I told them, when we wanted to do sports together, that I could not join and then they said they don't want to hang out with me anymore ... and then the friends left me alone." (Interview 8)</i>
Communication	At work		Participants describe how they communicate at work that they have a shunt	<i>P: "Yes, they know about my disease and about the shunt." (Interview 8)</i>
	With new people		Participants describe how they communicate with new people	<i>P: "No, I do not talk about the shunt." (Interview 3)</i>

Category system - example