Hydrocephalus: Cognitive and Behavioural Implications

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Overview

- Background
- Outcome improvements
- Cognitive and behavioural difficulties
- Cognitive assessment
- Cognitive profiles
- Triangulating data: ASBAH funded project
- Implications
- Interventions

Background

- Work as a Neuropsychologist in a multidisciplinary clinic in London
- Individuals with hydrocephalus and spina bifida visit once a year
- Full day of appointments with OT, continence advisor, living advisor, consultant and psychologist

- Discussing findings from an ASBAH 2 year funded project focused on cognitive & behavioural difficulties

Improved outcomes

Associated with:

- Early diagnosis and early intervention
- Advances in treatments
- Antibiotic - impregnated shunt materials
- Heightened awareness

Results in:

- Improvements in intellectual functioning

However - subtle cognitive difficulties can remain

Cognitive difficulties

Clare: 29 (GP receptionist)

- appears calm, confident and articulate
- Reports memory, calculation and spatial difficulties
- Afraid that people think she's not quick to learn or clever
- Born worrier, anxious and very outspoken
- Husband reports minimal memory difficulties

Sam: 25 (unemployed)

- Reports some learning and memory difficulties
- Reports sequencing and organisation difficulties that he finds frustrating
- Often feels very depressed and isolated
- Mum reports selective memory and behaviour outbursts

Common experiences

- Remember struggling with calculation and absorbing information at school
- Experienced unsuccessful job interviews
- Experienced forgetting & mistakes in the workplace
- Unaware of extent and impact of cognitive difficulties linked to hydrocephalus - **self-critical & frustrated**
- Aware that others misperceive their strengths and weaknesses
- Mixed success with using strategies - **e.g asking for extra time to prepare and absorb information**

Cognitive assessment

Assess:

- processing speed
- different components of attention e.g. sustained attention, selective attention
- learning ability
- different components of memory e.g long term and short term memory
- executive functioning
- language production **and** comprehension

Note - wide variability - impact for education

Cognitive tasks

- Processing speed and attentional flexibility and assessed using Trail making task
- Language understanding assessed using WAIS vocabulary and DKEFS Proverbs
- Executive functioning assessed with verbal fluency tasks
- Learning and memory functioning assessed using Hopkins list learning and WMS story recall

Intriguing modal cognitive profile

Strengths

- Elaborate use of language
- Verbal IQ
- Working memory performance
- Long term memory performance
- Forthright manner

Weaknesses

- Poor comprehension
- Poor calculation
- Poor learning
- Poor short term memory
- Poor executive function
- Poor strategy use
- Attentional deficits

Implications

- Self - perception
- Perception of carers and professionals
- Essential for education programme
- Essential for goals and outcomes

Cognitive assessment provides baseline and can be used to monitor change associated with shunt blockage

Behavioural assessment

Assess:

- Anxiety and/or depression
- Anger, frustration, irritability
- Emotional regulation
- Empathy
- Insight
- Situational difficulties e.g. novelty
- Coping strategies
- Self-esteem and self-perception
- Fears, hopes and dreams

Behavioural assessment

- Hospital Anxiety and Depression Scale
- Behavioural assessment questionnaire
- Observation
- Self report
- Carer report

- Reveals need for more detailed assessment tools

Psychosocial consequences

- Mood disorders including depression, anxiety, mood swings, poor emotional regulation
- Lowered self-esteem
- Perceived difficulties
- Actual behavioural difficulties
- Disinhibition
- Agitation/frustration
- Apathy
- Impact on family, friends, peers, educators and carers (esp. throughout child development and adolescence)

Rationale for our study

- Individuals with HC often have cognitive impairments which range from subtle to disabling
- Anecdotally, insight varies as does recognition of difficulties by family, friends and employers
- Focus on
  - cognitive and behavioural difficulties and more crucially their impact on day-to-day life
  - information regarding effective cognitive and social strategies

- 3-stage clinical project funded by ASBAH (Iddon, Loveday, Edginton, Morgan & Pickard)
- Aims to formulate useful guidelines for dissemination to clients, their family, their employers and their clinicians

Stage 1

Development of a new questionnaire to assess:

- the impact of cognitive and behavioural difficulties on everyday lives in adults with hydrocephalus
- the insight/perception of individuals with HC and how this links to others' perceptions

Plan to make questionnaire freely available to use as a standardised clinical tool for adults with HC

CONFIDENTIAL SURVEY- SERVICE USER ***Date today:*** ----------

We are conducting a survey to find out more about certain aspects of hydrocephalus and spina bifida. We want to get a better understanding of some of the difficulties you may have and in particular we want to know whether you are receiving the right kind of support and guidance. For section 1 to 4 we would like you to read the statements given and decide how true they are of you. There are no right or wrong answers and it is important that you answer all questions. If you feel that no answers are quite right then please just choose the answer that you think is closest. For section 5 to 8 we are asking some general questions. Please do your best to answer all of these. If you would like any help with writing some of the answers or would prefer not to complete the questionnaire please speak to the person who gave you the questionnaire.

This questionnaire is entirely confidential and will not directly affect your treatment at Chelsea & Westminster. However, we hope it will provide us with the information we need to continue improving services here and throughout the country and that ultimately you and others will benefit.

Please FILL IN THE CIRCLE that best represents your answer to HOW TRUE the following statements are about you.

	Not True	Partly true	Quite true	Very true
SECTION 1: MEMORY AND CONCENTRATION				
1. I am forgetful	O	O	O	O
2 I find it easy to recall passwords and PIN numbers	O	O	O	O
3. I am not easily distracted	O	O	O	O
4. I am a quick learner	O	O	O	O
5. I feel that my memory is no worse than most other peoples	O	O	O	O
6. I have difficulties with calculations, such as adding up or subtracting	O	O	O	O
7. I have difficulty concentrating (E.G. on a TV program)	O	O	O	O
8. I have no difficulty following a conversation	O	O	O	O
9. I get distracted and lose my train of thought	O	O	O	O
10. I generally need things to be explained to me very carefully and sometimes more than once	O	O	O	O
11. I enjoyed learning at school	O	O	O	O
12. At school/college I found studying frustrating and stressful	O	O	O	O
13. At school/college/work I often feel/felt that my achievements did not match my efforts	O	O	O	O
14. I am a slow learner	O	O	O	O

Questionnaire

Sections

1. Memory & attention/concentration
2. Planning & organization
3. Behaviour
4. Emotional & social
5. Strategies*
6. Service provision*
7. Psychological assessment & treatment*
8. General Questions*

(* indicates qualitative section)

Stage 2

Triangulate data

- Aim to correlate self-reported difficulties with observed difficulties and actual neuropsychological performance on a detailed battery of tasks that assesses memory, attention, executive functioning, language, performance IQ

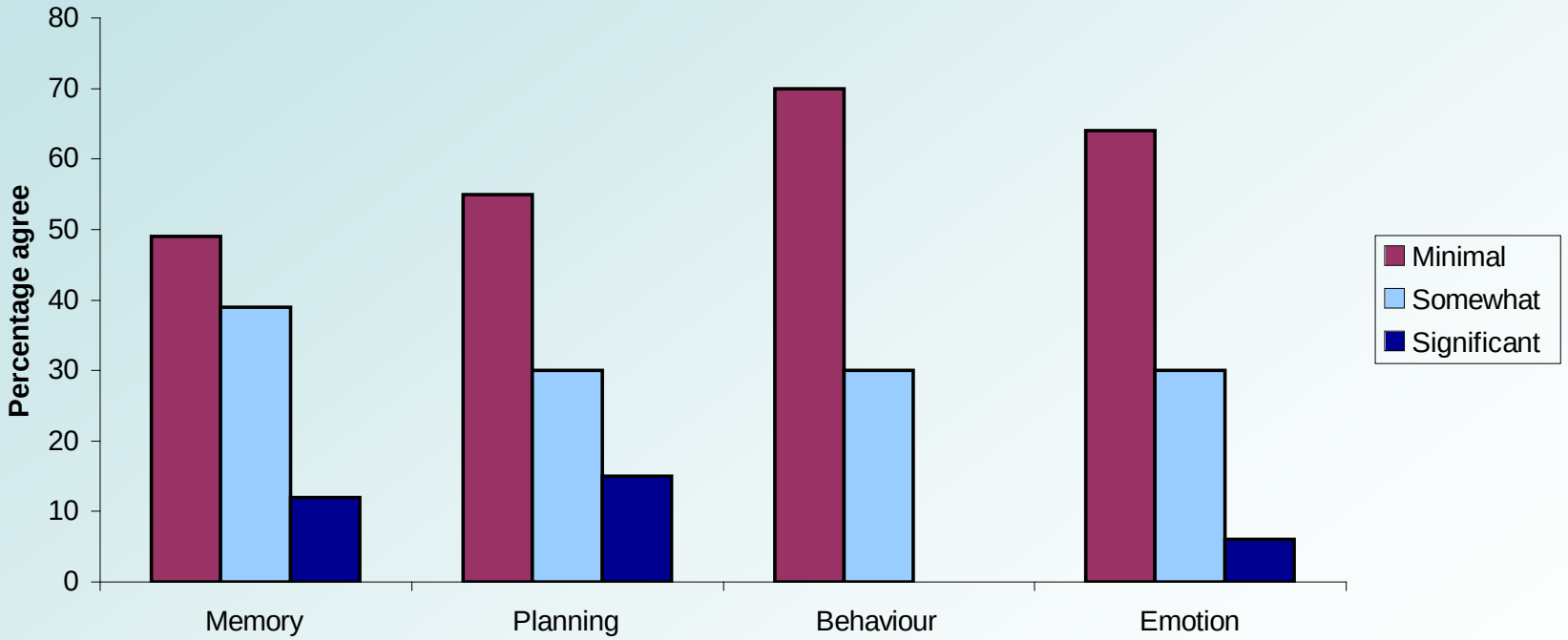
Study design

- Questionnaire data for 80 individuals with HC (with and without SB) and significant other pairs recruited in the multidisciplinary clinic at Chelsea and Westminster

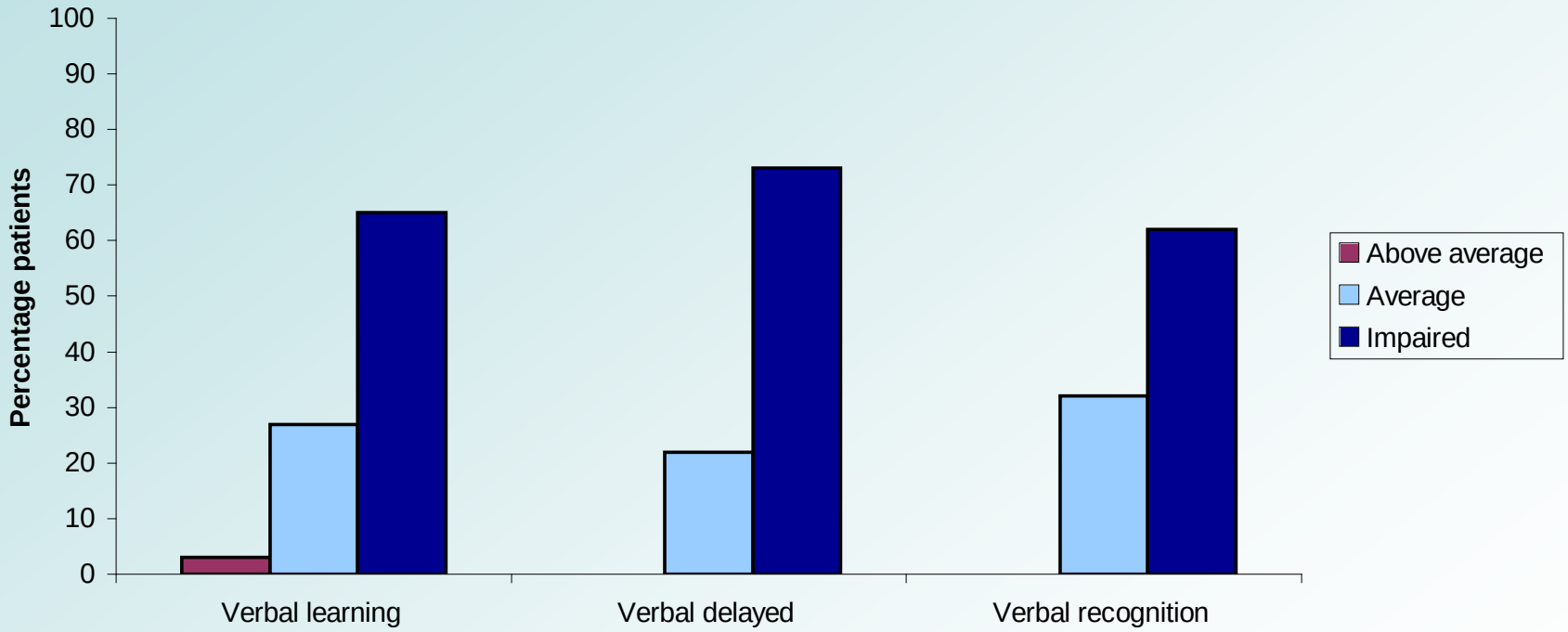
- Neuropsychological data for 30 (14:16 male to female ratio, mean age 36) of these clients to formally assess memory, planning and attention

- More detailed neuropsychological assessments for 30 (14 males; 16 females, mean age 34) of these clients

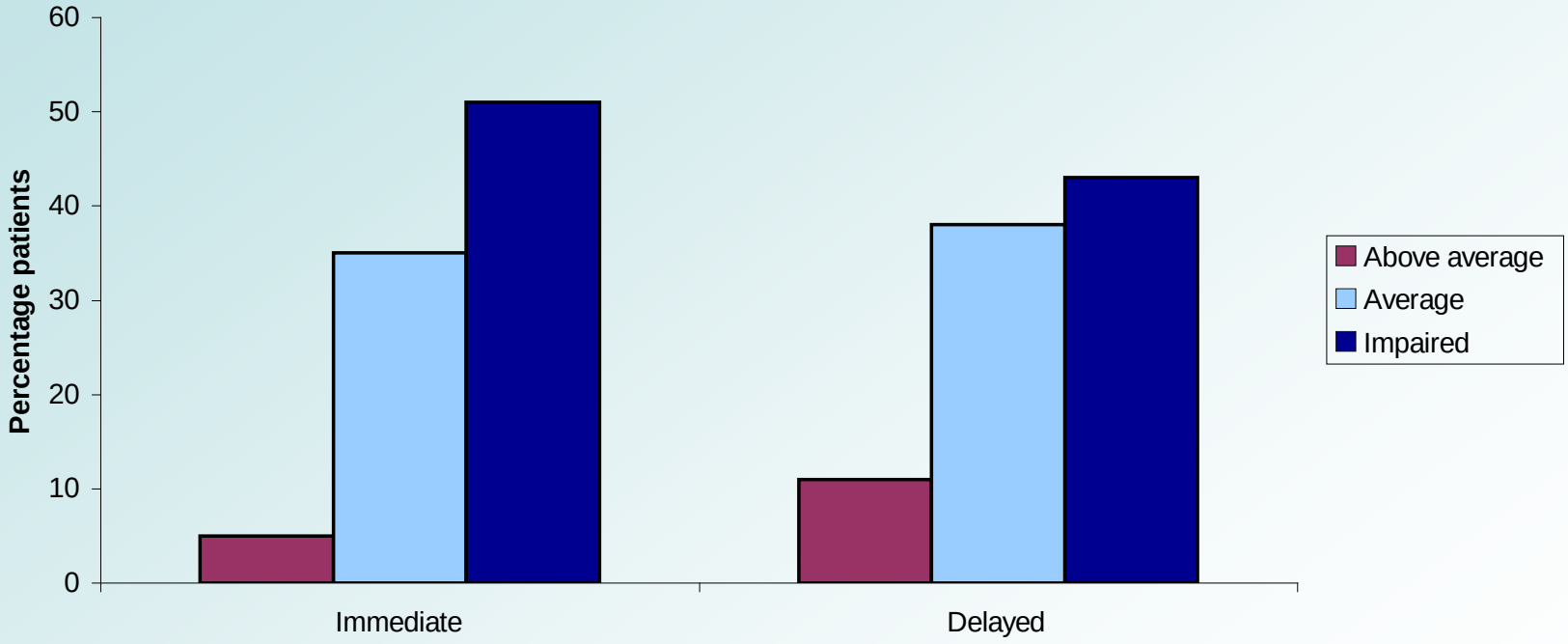
Self-reported difficulties using the Questionnaire (80 participants)



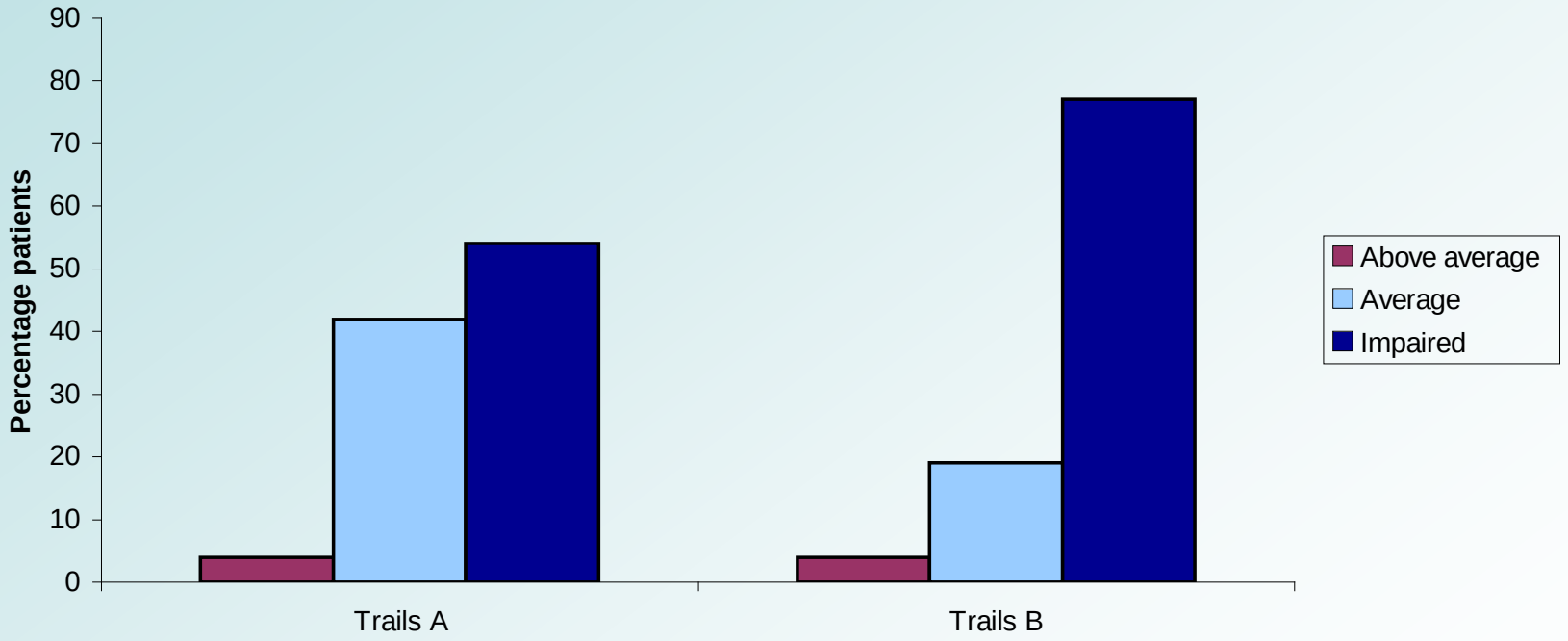
Verbal memory performance on the Hopkins memory task



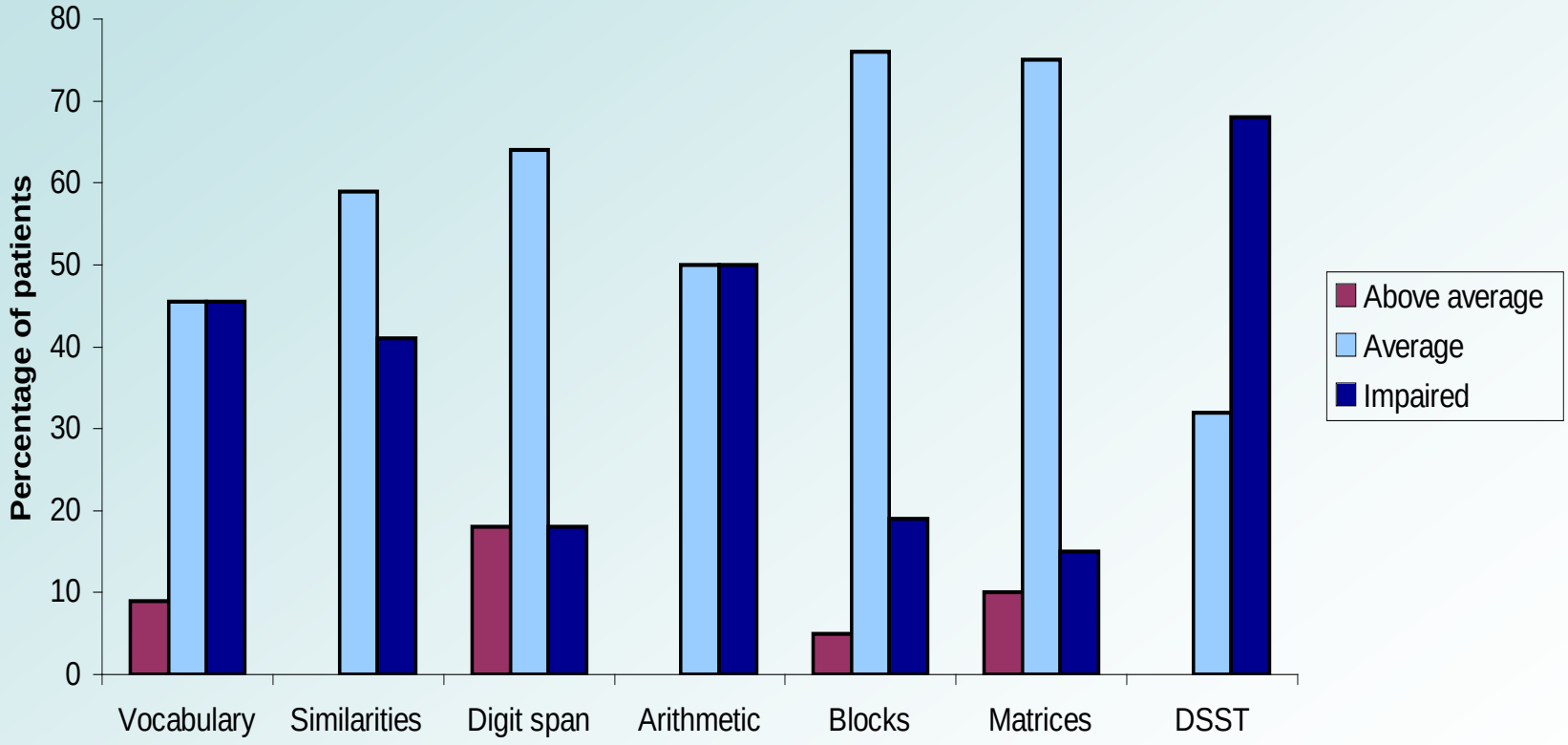
Complex memory performance on Weschler logical story recall



Switching performance on the Trail-making task



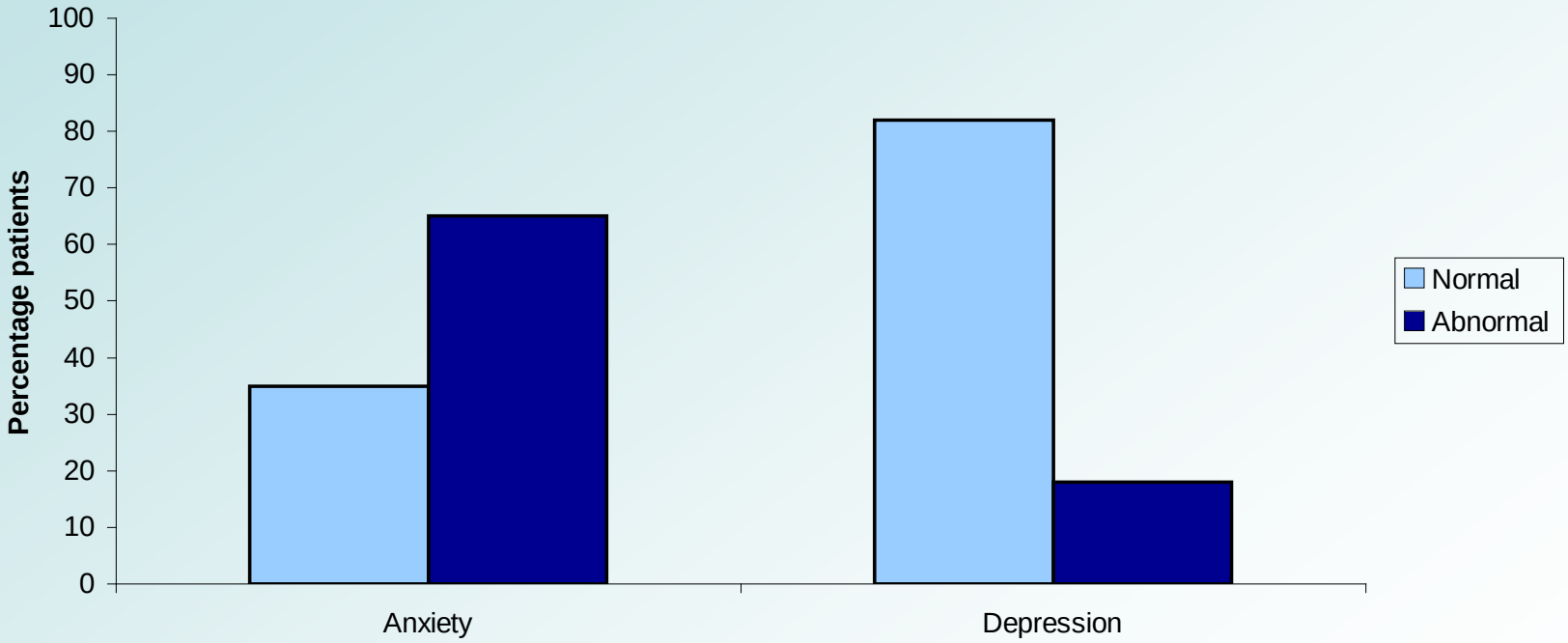
WAIS performance IQ measures



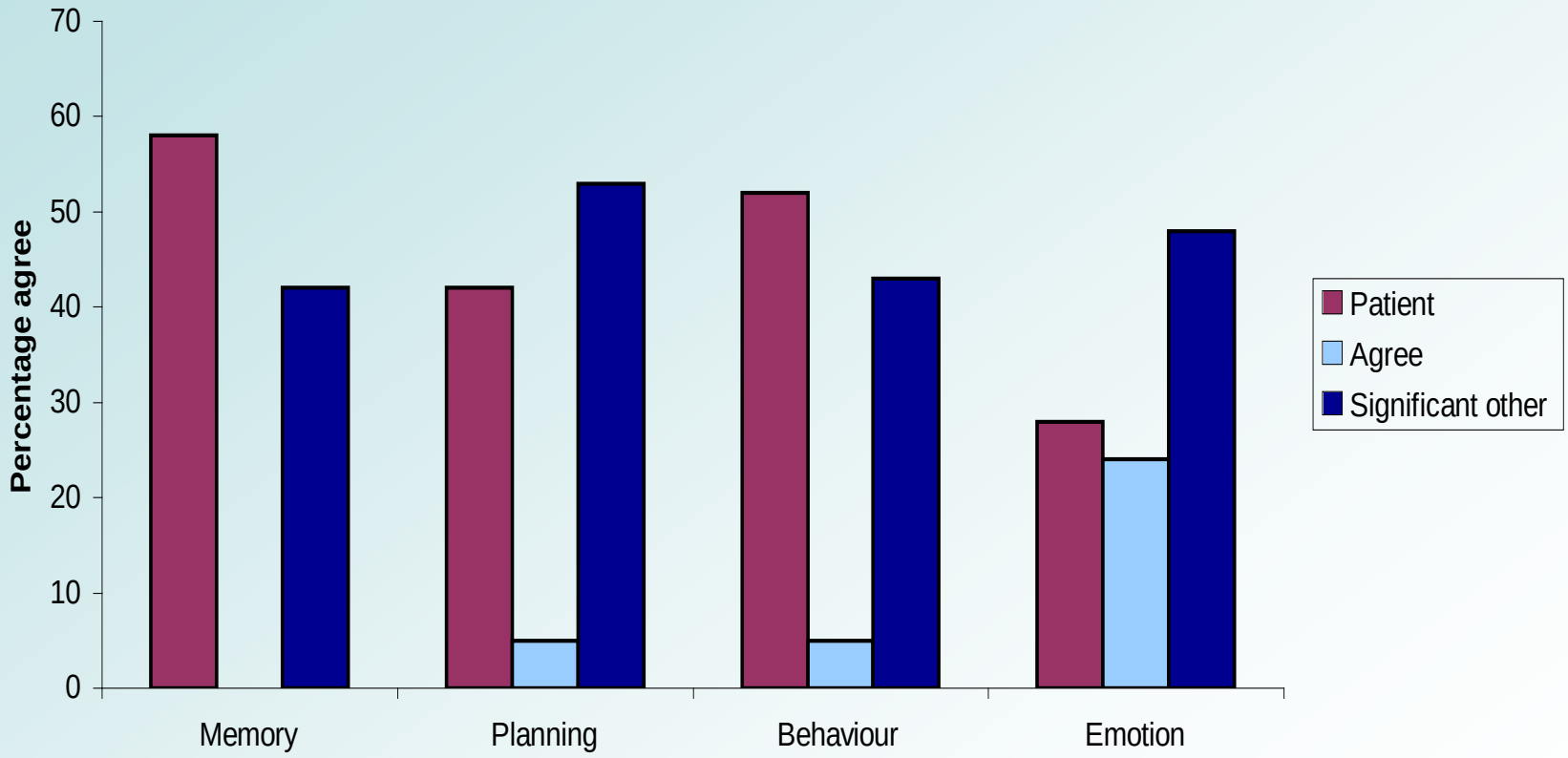
Initial findings

- Minimal memory and attentional difficulties self-reported by individuals with HC
- Contrasts with actual difficulties in verbal memory learning, recall and recognition and attentional switching
- Further contrasts with documented preserved performance IQ measures and working memory performance in the sub group although good use of vocabulary can mask underlying comprehension difficulties

Anxiety and depression levels using the HADS (n=80)



Disparity of insight (n=80)



Summary

- Confirmation of modal profile - strengths and weaknesses in cognitive areas e.g. average working memory in contrast to difficulties with delayed short term memory recall
- Range of difficulties appear to be underestimated by individuals with HC
- Lack of strategy use indicated
- 60% of our participants report increased anxiety
- Bimodal profile of disparity between individuals with HC and their significant others that requires further exploration

Implications

- Cognitive difficulties have wide ranging impact on everyday functioning
- Need to increase understanding of cognitive profile and specific cognitive strengths and weaknesses for individuals with HC, relatives, teachers and employers
- Reduced insight has implications for strategy use and cognitive interventions
- Disparity of insight needs to be further explored
- Questionnaire a useful tool to triangulate questionnaire perspectives with objective neuropsychological data

What's the next step?

- Primary aim to improve insight and assess disparity
- Individual assessment necessary to identify pattern of strengths and weaknesses
- Assess willingness for strategy interventions & establish agreed behavioural interventions
- Adopt ecological approach to assessment & targeted intervention **e.g for preparation, time & finances**
- Note lack of systematic evidence-based studies - these findings, tools and interventions to be made available
- We will be discussing interventions tomorrow at the workshop - **time to absorb and plan your questions!**

Acknowledgements

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