

Information needs of parents of children with ADHD

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Background

- Information acquisition – coping mechanism in disability and chronic illness (Cohen & Lazarus, 1979)
- Information = Knowledge = Empowerment
- Only study in Australia on information needs of parents was on children less than 5 years of age (FaCS, 2004)



Background

- We know that parents draw on multiple sources for information on ADHD
- However we do not know what they access and how they would like information to be given
- First study in Australia - parent perspective specific condition



Aims

- To determine what information sources parents have accessed
- To determine the quality of sources accessed
- To identify what content parents find most important
- To identify preferred information mode
- To identify if information needs change over a period of time since diagnosis



Methods

- Cross sectional survey of parents of children with ADHD
- Data collected via 15 item questionnaire specifically designed for this study
- Recruitment : Parents attending clinics at Centre for Community Child Health and a community sample



Methods

- Age of child, time since ADHD diagnosis, medication usage, availability of DVD, video and computer, parental education level
- List of 19 sources provided
- Quality of Sources

usefulness

trustworthy

up to date

easy to understand

Five Point
Agreement
Scale

- Rank preferred information modes



Methods : Measures

- Two points of time – diagnosis / survey
- Rating – How Important ? 4 point importance scale
- Content :-

ADHD symptoms

Causes

Associated problems

Medication

Behaviour management

Educational strategies

Latest research

Social skills

Dealing with other children

Centrelink benefits



Data analysis

- 99 Questionnaires returned; 96 analysed
- Percentages calculated for positive response to each question
- Rating scales : dichotomised strongly agreed and agreed as positive and extremely important and very important as positive responses

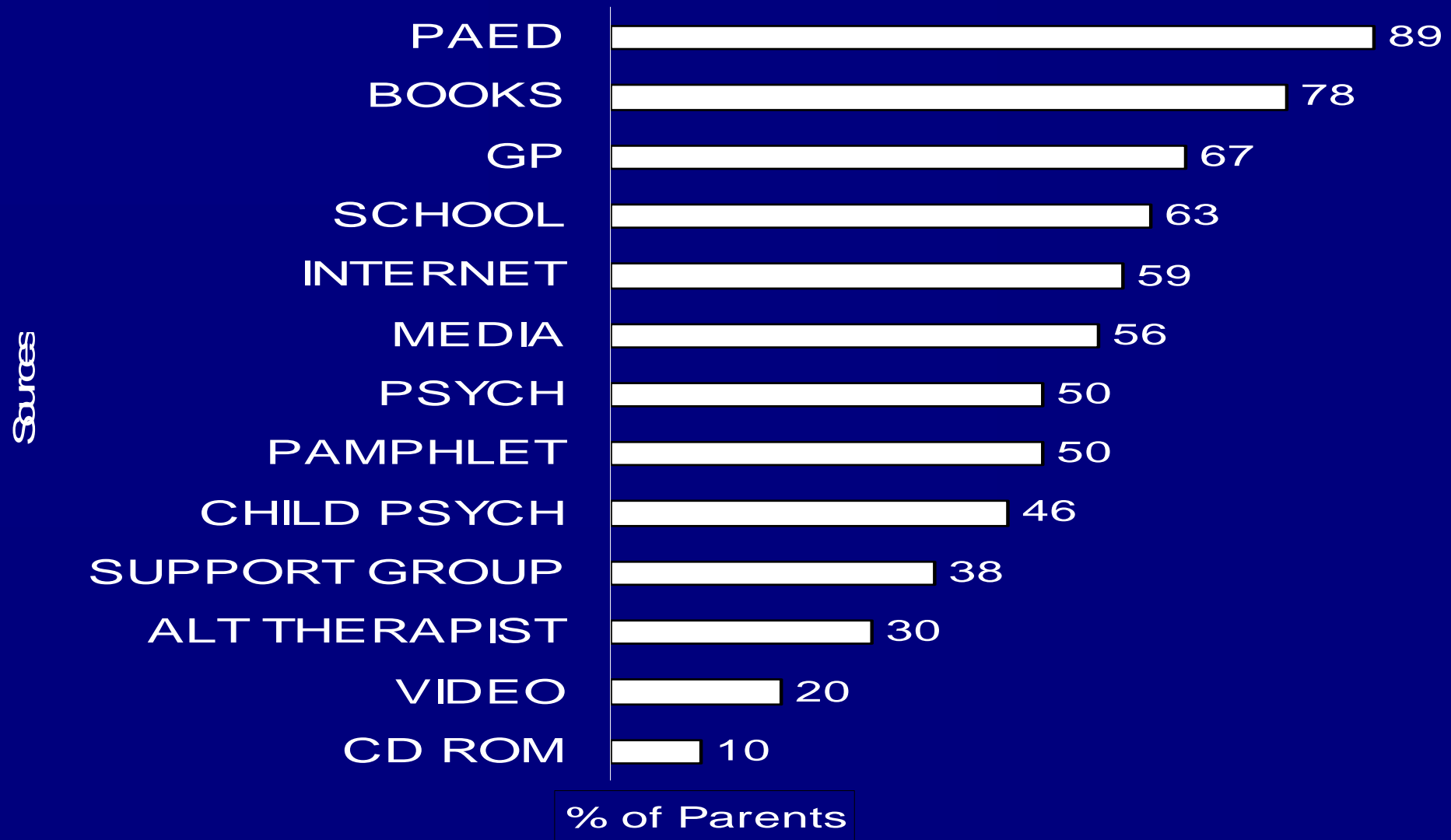


Results : Demographics

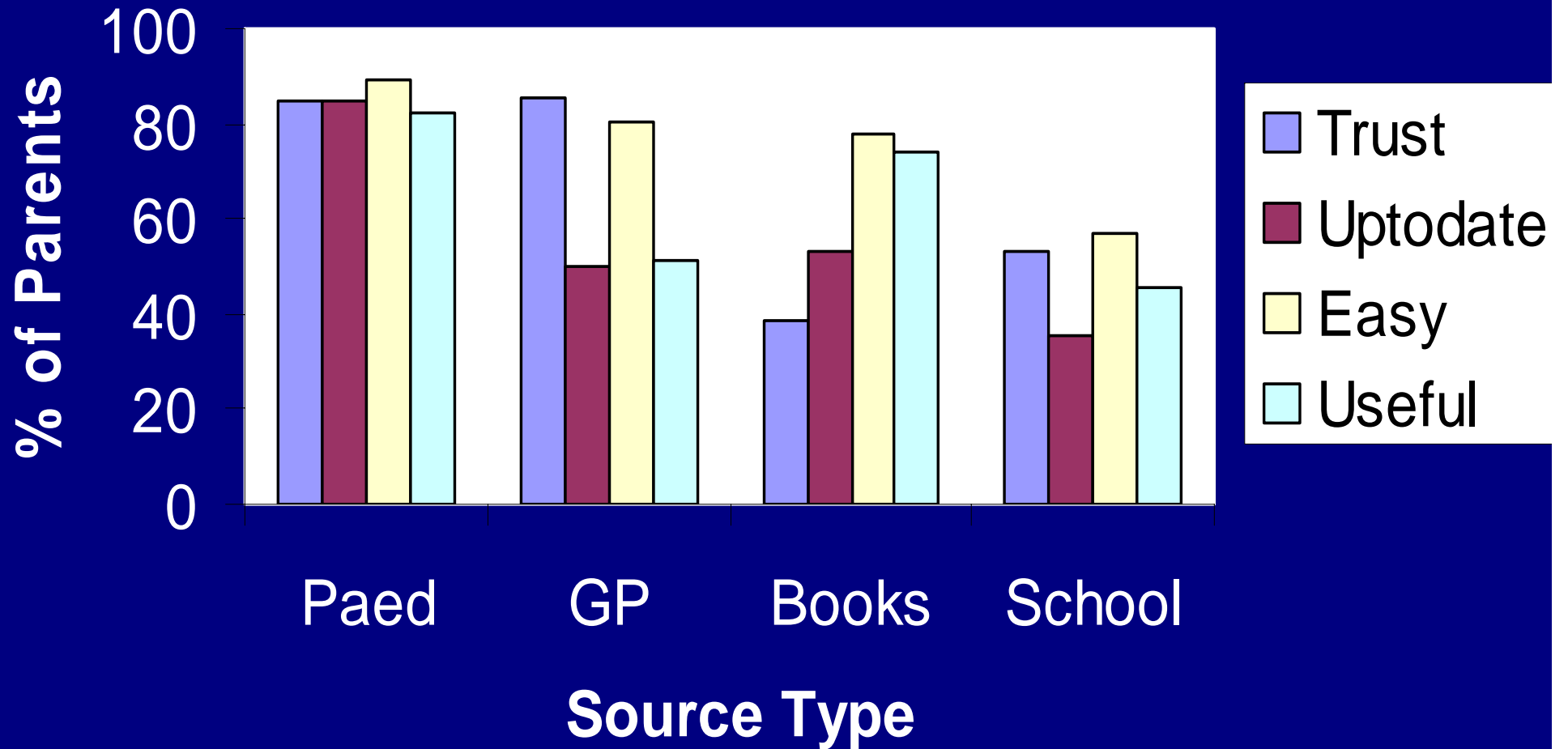
Parameters		%
Age Group	5-12 yrs	79
	> 13 yrs	21
Time since diagnosis	> 1 yr	83
Parental Education	Degree (Mother)	34
	Degree (Father)	34
Avail of technology	PC with Internet	74
	PC with CD ROM	83
	DVD	94



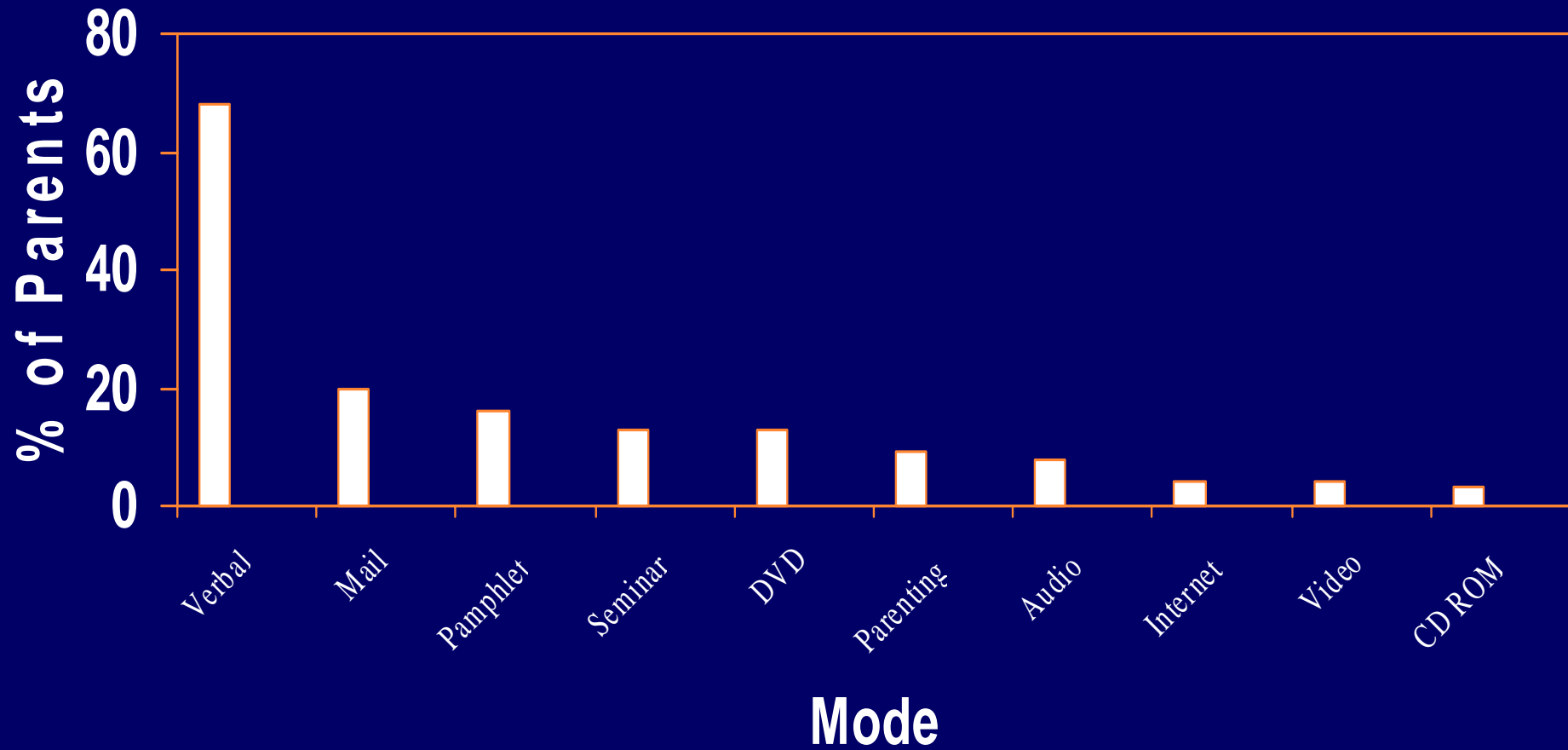
Sources Accessed



Quality of Sources



First Preference



Results

- All aspects of ADHD important
- Causes/ symptoms - at diagnosis
- Majority indicated behaviour management, education and building up social skills - important at all times
- No change - time since diagnosis, age of the child



Conclusions

- Parents access multiple sources
- Spoken word – professional, in an easy, up-to-date format preferred
- Consistent with other studies (Mitchell & Sloper, 1992; FaCS 2004)
- Technology has not replaced the human element
- Information targeted and continuous process



Implications/Suggestions

- Consult parents while designing information materials and determining the mode of delivery
- Face-to-face exploration with parents via focus groups
- Professionals - information is an important aspect of consultation, tailored to needs



Acknowledgements

- Raelene McNaughton, CCCH
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