CULTURAL INFLUENCES ON THE TREATMENT FOR
ADHD IN WESTERN AUSTRALIA

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This thesis is presented for the degree of
Doctor of Philosophy

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2015
I dedicate this thesis to my father, Monotosh Ghosh. He values education and has always wanted me to have a PhD. His unconditional love and support regardless of the geographical distance between us has been constant motivation and inspiration for this journey. His recent dementia has been instrumental in my ability to overcome many challenges.
ABSTRACT

BACKGROUND

In Australia, the rate of psychostimulant medication for Attention Deficit Hyperactivity Disorder (ADHD) is reported to have been increasing, similar to the trends observed in the USA, Canada and Europe. Demographic variables such as age, gender and socioeconomic status have been consistently found to have an association with the prevalence of psychostimulant treatment for ADHD. Less is known, however, about the sociocultural context of stimulant treatment for ADHD. It is well recognised, after all, that individuals’ ethnic and cultural backgrounds make a significant contribution to their health behaviours and effective access to health care.

AIMS

This thesis investigates differentiating patterns of prescription stimulant medications for the treatment of ADHD in Western Australia (WA). In particular, it studies the influences of country of birth and race on the use of stimulant medication for ADHD; and explores individuals’ perceptions of ADHD behaviour, the meaning that the diagnosis carries for them and their attitudes towards stimulant treatment.

METHODOLOGY

This thesis was divided into two parts: Part A and Part B. The methods in Part A involved two quantitative research studies to investigate the influence of country of birth and race on stimulant medication treatment for ADHD. Using whole-population linked data from the WA Data Linkage System (WADLS), a cohort of people was selected from the WA Birth Registry and WA Hospital Morbidity Data Collection from 1980-2007, and followed to identify any stimulant prescription records for ADHD between 2003 and 2007. Univariate and multivariate logistic and linear regression models, as well as Cox proportional hazards regression models, were used in Statistical Package for Social Science (SPSS) to examine factors associated with stimulant use.

The methods in Part B, on the other hand, employed qualitative research techniques to explore how individuals’ perceptions of ADHD behaviour and attitudes towards stimulant medication influenced their decision making process about ADHD treatment.
Semi-structured, in-depth, face-to-face interviews were carried out with eight participants from Anglophonic background, who themselves or their children were diagnosed with ADHD. Thematic analysis was undertaken on the qualitative data.

RESULTS

Results from the two quantitative studies in thesis Part A revealed significant country of birth disparities in stimulant medication treatment for ADHD in WA. In the first study, a total of 13,555 individuals born in WA in 1980–2007 were prescribed stimulant medications for ADHD treatment between 2003 and 2007. Of them the majority (88.6%) had parents born in traditionally Anglophonic nations such as those of Australia, Europe or North America, while a much smaller proportion (5.4%) had one or both parents born in non-Anglophonic nations in Africa, Asia, the Middle East or South America. Individuals of parents born in non-Anglophonic nations were 83% less likely to be treated with stimulants (OR=0.17, 95%CI 0.14–0.21, p<0.001) than those of parents born in Anglophonic nations. The mean age at onset of stimulant use was also one year higher in those with parents born in non-Anglophonic nations compared with those who had parents born in Anglophonic nations.

The cohort in the second quantitative study comprised individuals who were admitted into WA hospitals for any reason for the first time by the age of 25 years. The findings from the second study were consistent with the apparent influence of country of birth observed in the first study. Of the 14,222 individuals who received stimulant treatment, 96.8% were born in Anglophonic nations. Individuals born in non-Anglophonic nations were approximately twice less likely to receive stimulants compared with those born in Anglophonic nations (OR 0.53, 95%CI 0.46–0.61, p<0.001). In the second study, non-Anglophonic individuals were three years older than their Anglophonic peers at the time of initial stimulant treatment. Both quantitative studies found that gender and geographic location were factors associated with variations in stimulant treatment use in WA.

The qualitative study uncovered three interrelated yet somewhat contradictory groups of themes: (i) ADHD symptoms as an impairment to achieving success, which can be a double-edged sword, but has to be fixed; (ii) ADHD diagnosis as a source of relief that alleviates fault and acknowledges familial inheritance; and (iii) ADHD treatment as the
result of a responsibility to be normal and to fit in with societal expectations. Collectively, these perceptions and meanings were powerful drivers of stimulant use.

CONCLUSION

Willingness to prefer stimulant medication treatment for ADHD behaviours is a pivotal sociocultural question that needs to be considered in developing interventions, policies and programs related to ADHD, to provide appropriate service levels and to achieve better lifecourse outcomes. This thesis contributes to an emerging literature, emphasising the importance of adopting ecologically sensitive clinical practices in relation to ADHD diagnosis and stimulant treatment.
ACKNOWLEDGEMENTS

As with every accomplishment of a dream, the completion of this dream has been a blessing. I felt privileged to study under the supervision of a global icon Winthrop Professor D’Arcy Holman who provided precise guidance, intellectual stimulation, insightful advice, optimism and encouragement throughout my journey to accomplish this dream. I extend my deepest gratitude for his patience in reading my drafts numerous times and assisting me with revisions. I could not have imagined having a better supervisor and a mentor for my PhD study. I also appreciate his generosity in providing me with the best possible computing resources during my candidature.

I express my sincere thanks and appreciation to Professor David Preen, my co-supervisor who challenged me to provoke my thinking, and helped with his great expertise, professional and scholarly judgment – vital for my doctoral learning process.

I owe a special gratitude to Professor Colleen Fisher for reviewing the manuscript of the qualitative study in the thesis, providing brilliant insightful feedback and enhancing the lens through which I analyze qualitative data.

I am grateful to the University of Western Australia for providing me with the financial support for three and half years during my candidature, as a recipient of the Australian Postgraduate Award, and Top-Up Scholarship.

I would like to acknowledge the significant role of the WA Department of Health Data Linkage Unit, Hospital Morbidity Data Collection, Midwives Notifications and Pharmaceutical Services Branch for the provision of linked data. In particular, my thanks to Alexandra Godfrey, Carol Garfield, Di Rosman, Susan Gontaszewski and Alpa Dodhia for being helpful with and prompt to my queries.

My heartfelt thanks go to all the participants who must remain anonymous. Their willingness to give time and to share their perspectives in the qualitative aspect of the thesis without immediate benefit to them is greatly appreciated.
I thank the Professional Advisory Board members of the Learning and Attentional Disorder Society (LADS) for allowing me to attend ADHD support groups and distribute flyers for possible participant recruitment.

A special thanks to Dr. Krystyna Haq, Graduate Education Officer, UWA, for proofreading the thesis. My humble thanks go to past and present staff who provided positive encouragement and at times, hands on help. In particular, Dr. Anna Kemp, Dr. Louise Stewart, Dr. Alex Bremner and Dr. Gavin Pereira for helping me with SPSS; Dr. Qun Mai and Dr. Nita Sodhi for sharing their insights on the doctoral journey; Bernie Jaw and his team for continuous IT support throughout my candidature.

Finally, I am deeply indebted to my family for giving me unconditional love and support. This journey would have been impossible without the constant encouragement and help from the family. I owe a lot to my children Omrik and Ovik. Their love, understanding and bearing my absence from their sports, music performance and award presentations from time to time are priceless. I could not be blessed with better children. You are my pride.
# TABLE OF CONTENTS

ABSTRACT

V

ACKNOWLEDGEMENTS

V

TABLE OF CONTENTS

VII

LIST OF FIGURES

XIII

LIST OF TABLES

XIV

STATEMENT OF CANDIDATE CONTRIBUTION

XV

AWARDS AND PRESENTATIONS

XVI

DECLARATION OF THESIS PUBLICATION

XVII

GLOSSARY OF TERMS

XVIII

LIST OF ABBREVIATIONS

XX

CHAPTER 1 INTRODUCTION

1

1.1 OVERVIEW OF ADHD

1

1.2 USE OF STIMULANT MEDICATION FOR ADHD

1

1.3 RATIONALE FOR THESIS

3

1.4 AIMS OF THESIS

4

1.5 RESEARCH APPROACH

4

1.6 SCOPE OF THESIS

5

1.7 STRUCTURE OF THESIS

5

CHAPTER 2 LITERATURE LANDSCAPE

9

2.1. INTRODUCTION

9

2.2. METHODOLOGY FOR LITERATURE SEARCH

9

2.3. WHAT IS ADHD?

11

2.4. PREVALENCE OF ADHD

12

2.5. COMORBIDITIES

13

2.6. OUTCOMES OF ADHD

14

2.7. ECONOMIC BURDEN

14

2.8. AETIOLOGICAL CONTROVERSY WITH ADHD

15

2.8.1. ADHD – a neurological condition

16

2.8.2. ADHD – a genetic condition

16

2.8.3. ADHD – an environmental condition

17

2.8.4. ADHD – a biopsychosocial condition

18

2.8.5. ADHD – a socially constructed illness

19

2.9. CULTURAL PERCEPTIONS OF THE AETIOLOGY OF ADHD

19

2.10. CULTURE AND DIAGNOSIS OF ADHD

21

2.11. CULTURAL DIFFERENCES IN INTERPRETATION OF EXTERNALISING BEHAVIOUR

23

2.12. CULTURAL GUIDELINES IN DSM-V DIAGNOSTIC TOOL

24

2.13. TREATMENT AND MANAGEMENT OF ADHD

24

2.13.1. Psychosocial treatment

26

2.13.2. Pharmacological treatment

27
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.13.3. Multimodal treatment</td>
<td>28</td>
</tr>
<tr>
<td>2.14. USE OF STIMULANT TREATMENT</td>
<td>29</td>
</tr>
<tr>
<td>2.15. STIMULANT MEDICATION USE IN AUSTRALIA</td>
<td>29</td>
</tr>
<tr>
<td>2.16. STIMULANT MEDICATION USE IN WESTERN AUSTRALIA</td>
<td>30</td>
</tr>
<tr>
<td>2.17. CONTROVERSY OVER THE STIMULANT TREATMENT FOR ADHD</td>
<td>31</td>
</tr>
<tr>
<td>2.18. DISPARITIES IN THE USE OF STIMULANT TREATMENT</td>
<td>32</td>
</tr>
<tr>
<td>2.19. CULTURAL VARIATIONS IN STIMULANT TREATMENT USE</td>
<td>33</td>
</tr>
<tr>
<td>2.20. CULTURAL EXPLANATORY MODEL</td>
<td>34</td>
</tr>
<tr>
<td>2.21. ADHD HELP-SEEKING BEHAVIOUR MODEL FOR DIVERSE CULTURES</td>
<td>34</td>
</tr>
<tr>
<td>2.22. CULTURAL STIGMA AND UTILISATION OF STIMULANT TREATMENT</td>
<td>37</td>
</tr>
<tr>
<td>2.23. USE OF STIMULANT MEDICATION FOR ADHD IN PEOPLE WITH DIVERSE CULTURAL AND LINGUISTIC BACKGROUNDS IN AUSTRALIA</td>
<td>38</td>
</tr>
<tr>
<td>2.24. USE OF STIMULANT TREATMENT FOR ABORIGINALS</td>
<td>39</td>
</tr>
<tr>
<td>2.25. SUMMARY OF LITERATURE REVIEW</td>
<td>40</td>
</tr>
<tr>
<td><strong>CHAPTER 3 OVERALL THESIS DESIGN</strong></td>
<td>43</td>
</tr>
<tr>
<td>3.1 INTRODUCTION</td>
<td>43</td>
</tr>
<tr>
<td>3.2 THESIS STRUCTURE AND DESIGN</td>
<td>43</td>
</tr>
<tr>
<td>3.2.1 Part A - Quantitative study</td>
<td>45</td>
</tr>
<tr>
<td>3.2.2 Part B - Qualitative study</td>
<td>46</td>
</tr>
<tr>
<td>3.2.3 Study findings</td>
<td>47</td>
</tr>
<tr>
<td>3.3 DATA STORAGE AND SECURITY</td>
<td>47</td>
</tr>
<tr>
<td>3.4 ETHICAL CONSIDERATIONS AND APPROVAL</td>
<td>48</td>
</tr>
<tr>
<td>3.5 CHAPTER SUMMARY</td>
<td>50</td>
</tr>
<tr>
<td><strong>CHAPTER 4 QUANTITATIVE METHODOLOGY</strong></td>
<td>51</td>
</tr>
<tr>
<td>4.1 INTRODUCTION</td>
<td>51</td>
</tr>
<tr>
<td>4.2 WA DATA LINKAGE SYSTEM (WADLS)</td>
<td>51</td>
</tr>
<tr>
<td>4.3 WA FAMILY CONNECTIONS GENEALOGICAL SYSTEM (WAFCGS)</td>
<td>54</td>
</tr>
<tr>
<td>4.4 PROCESS OF LINKAGE</td>
<td>54</td>
</tr>
<tr>
<td>4.5 QUANTITATIVE STUDY ONE</td>
<td>57</td>
</tr>
<tr>
<td>4.5.1 Data source for quantitative study one</td>
<td>57</td>
</tr>
<tr>
<td>4.5.2 Sample selection</td>
<td>62</td>
</tr>
<tr>
<td>4.5.3 Variables and measurement</td>
<td>63</td>
</tr>
<tr>
<td>4.6 QUANTITATIVE STUDY TWO</td>
<td>68</td>
</tr>
<tr>
<td>4.6.1 Data source for quantitative study two</td>
<td>69</td>
</tr>
<tr>
<td>4.6.2 Sample selection</td>
<td>71</td>
</tr>
<tr>
<td>4.6.3 Variable and measurements</td>
<td>71</td>
</tr>
<tr>
<td>4.7 STATISTICAL ANALYSIS FOR QUANTITATIVE STUDY ONE &amp; TWO</td>
<td>75</td>
</tr>
<tr>
<td>4.8 CHAPTER SUMMARY</td>
<td>75</td>
</tr>
</tbody>
</table>
CHAPTER 11 DISCUSSION AND THESIS CONCLUSIONS 157

11.1. INTRODUCTION 157

11.2. STRENGTHS OF THE STUDY 157
   11.2.1. Study design 157
   11.2.2. High quality health administration data 158
   11.2.3. Family connections genealogical data 158
   11.2.4. Large sample size 159
   11.2.5. Internal validity 159

11.3. INTEGRATION 159

11.4. OVERVIEW OF MAJOR FINDINGS 160
   11.4.1. Country of birth influences on stimulant medication treatment 161
   11.4.2. Delayed onset of stimulant treatment according to culture 161
   11.4.3. Variations in the stimulant treatment use according to Aboriginal status 162
   11.4.4. Disparities across gender, socioeconomic status and residential remoteness in stimulant treatment 163
   11.4.5. Individuals' perceptions of ADHD and attitudes towards stimulant treatment 164

11.5. PERSONAL REFLECTIONS 164

11.6. LIMITATIONS 165
   11.6.1. Cohort selection 165
   11.6.2. Completeness of linked health administrative data 166
   11.6.3. Individual's ethnic information 166
   11.6.4. Individual's migration status information 167
   11.6.5. Accuracy of Aboriginal data 167
   11.6.6. Small sample size 167
   11.6.7. Absence of participants from socioeconomically and geographically diverse background 168
   11.6.8. Absence of participants with culturally diverse background 168
   11.6.9. Absence of Aboriginal participants 169

11.7. IMPLICATIONS OF THESIS FINDINGS 169
   11.7.1. Health policy and practice implications 170
   11.7.2. ADHD interventions and policy framework appropriate to the Aboriginal population 170
   11.7.3. Training for health care professionals regarding cultural differences in understanding of ADHD and stimulant treatment 171
   11.7.4. Increasing sensitivity among health care professionals 171
   11.7.5. Development of regulation of stimulant use 171
   11.7.6. Recognition of cultural influences on ADHD treatment as a health priority area 172

11.8. AREAS FOR FUTURE RESEARCH 172
   11.8.1. Comparing stimulant medication use within the symptomatic population 172
   11.8.2. Different risk factors 173
   11.8.3. ADHD diagnosis and perception of ADHD in the Aboriginal population 173
   11.8.4. Different populations 174

11.9. THESIS CONCLUSIONS 174
REFERENCES

APPENDIX I CONFERENCE ABSTRACT

APPENDIX II CONFERENCE POSTER

APPENDIX III NOTIFICATION OF TREATMENT WITH STIMULANT MEDICATION

APPENDIX IV HOSPITAL INPATIENT SUMMARY FORM

APPENDIX V ADDITIONAL TABLE

APPENDIX VI FLYER FOR LPNO PARTICIPANTS

APPENDIX VII INFORMATION LETTER

APPENDIX VIII PARTICIPANT CONSENT FORM

APPENDIX IX INTERVIEW GUIDE

APPENDIX X DEMOGRAPHIC QUESTIONNAIRE

APPENDIX XI EXPLORING PARENTAL COUNTRY OF BIRTH DIFFERENCES IN THE USE OF PSYCHOSTIMULANT MEDICATIONS FOR ADHD: A WHOLE-POPULATION LINKED DATA STUDY

APPENDIX XII USE OF PRESCRIPTION STIMULANT FOR ATTENTION DEFICIT HYPERACTIVITY DISORDER IN ABORIGINAL CHILDREN AND ADOLESCENTS: A LINKED DATA COHORT STUDY

APPENDIX XIII “IT HAS TO BE FIXED”: A QUALITATIVE INQUIRY INTO PERCEIVED ADHD BEHAVIOUR AMONG AFFECTED INDIVIDUALS AND PARENTS IN WESTERN AUSTRALIA
<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Structure of the thesis</td>
</tr>
<tr>
<td>2</td>
<td>Four stages of ADHD help seeking behaviour model. Adopted from Eiraldi</td>
</tr>
<tr>
<td>3</td>
<td>Methodological framework of the thesis</td>
</tr>
<tr>
<td>4</td>
<td>Stages of the quantitative phase</td>
</tr>
<tr>
<td>5</td>
<td>Stages of the qualitative study</td>
</tr>
<tr>
<td>6</td>
<td>WA Data linkage system</td>
</tr>
<tr>
<td>7</td>
<td>Genealogical links between parents and child with stimulant records</td>
</tr>
<tr>
<td>8</td>
<td>Chain of links</td>
</tr>
<tr>
<td>9</td>
<td>Monitoring of Drugs of Dependence System database</td>
</tr>
<tr>
<td>10</td>
<td>Distribution of stimulant medication among parental country of birth by region and sub-region</td>
</tr>
<tr>
<td>11</td>
<td>Distribution of stimulant medication among individuals admitted into hospitals from 1980-2007, by region and sub-region</td>
</tr>
<tr>
<td>12</td>
<td>Aboriginal and non-Aboriginal cohort identification, group selection and exclusion criteria</td>
</tr>
<tr>
<td>13</td>
<td>Study design sample selection and exclusion criteria</td>
</tr>
<tr>
<td>14</td>
<td>Summary of key quantitative findings</td>
</tr>
<tr>
<td>15</td>
<td>Six phases of the analytic process</td>
</tr>
<tr>
<td>16</td>
<td>Perception towards ADHD and stimulant treatment choice</td>
</tr>
<tr>
<td>17</td>
<td>Model for stimulant treatment choice</td>
</tr>
</tbody>
</table>
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 1.</td>
<td><strong>MeSH</strong> terms in literature search</td>
<td>10</td>
</tr>
<tr>
<td>Table 2.</td>
<td>Summary of data sources for quantitative phase</td>
<td>58</td>
</tr>
<tr>
<td>Table 3.</td>
<td>Country of birth grouped by region and sub-region</td>
<td>64</td>
</tr>
<tr>
<td>Table 4.</td>
<td>Mapping country of birth according to Australian Bureau of Statistics</td>
<td>73</td>
</tr>
<tr>
<td>Table 5.</td>
<td>Characteristics of the participants in the study</td>
<td>82</td>
</tr>
<tr>
<td>Table 6.</td>
<td>Differences in stimulant use associated with parental country of birth and family characteristics</td>
<td>83</td>
</tr>
<tr>
<td>Table 7.</td>
<td>Comparing patient mean age at first stimulant used</td>
<td>85</td>
</tr>
<tr>
<td>Table 8.</td>
<td>Baseline demographic characteristics of Aboriginal and non-Aboriginal children and adolescents born in WA between 1980 and 2005</td>
<td>95</td>
</tr>
<tr>
<td>Table 9.</td>
<td>Hazard ratios and 95% confidence intervals of prescription stimulant medication in Aboriginal and non-Aboriginal children and adolescents born in WA</td>
<td>97</td>
</tr>
<tr>
<td>Table 10.</td>
<td>Comparison of prescription stimulant medication use for ADHD in Aboriginal and non-Aboriginal children and adolescents by metropolitan and non-metropolitan areas</td>
<td>98</td>
</tr>
<tr>
<td>Table 11.</td>
<td>Hazard ratios and 95% confidence intervals of prescription stimulant medication in Aboriginal children and adolescents</td>
<td>99</td>
</tr>
<tr>
<td>Table 12.</td>
<td>Characteristics of the study population according to stimulant medication use for ADHD</td>
<td>108</td>
</tr>
<tr>
<td>Table 13.</td>
<td>Odds ratios for the association of at least one record of stimulant treatment for ADHD with cultural and demographic factors</td>
<td>109</td>
</tr>
<tr>
<td>Table 14.</td>
<td>Mean age in years in those receiving a stimulant medication for ADHD according to cultural and demographic factors</td>
<td>110</td>
</tr>
<tr>
<td>Table 15.</td>
<td>Demographic information of participants</td>
<td>128</td>
</tr>
<tr>
<td>Table 16.</td>
<td>Key data elements and measurement</td>
<td>132</td>
</tr>
<tr>
<td>Table 17.</td>
<td>Demographic characteristics of the study participants</td>
<td>138</td>
</tr>
</tbody>
</table>
STATEMENT OF CANDIDATE CONTRIBUTION

I declare that the work in this thesis was carried out in accordance with the requirements of The University of Western Australia and Code of Practice for Research Degree Programs, and that it has not been submitted for any other academic award or any other university. Except where indicated by specific reference in the text, this thesis represents the original work undertaken by me as a PhD candidate. Under the guidance and expertise of my principal supervisor, Winthrop Professor D’Arcy Holman, and my co-supervisor Professor David Preen, I was responsible for: study conceptualisation and planning, study design, applying for ethics approval, applying for data collection from Department of Health Western Australia, data cleaning and statistical analysis, qualitative participant recruitment, field work, data collection and analysis. It was my core responsibilities to interpret the results and draft manuscripts and the thesis. Any views expressed in the thesis are mine. All co-authors provided advice on aspects of analyses, concepts and reviewed and made invaluable contributions to the manuscripts.

Additional training in data linkage and biostatistics were achieved through the completion of Winthrop Professor D’Arcy Holman’s course *Introductory Analysis of Linked Health Data*, as well as Biostatistics and Epidemiology units offered from the School of Population Health.
AWARDS AND PRESENTATIONS

Awards

1. Australian Postgraduate Award, University of Western Australia
2. Top-Up Scholarship, School of Population Health, University of Western Australia
3. Graduate Research Conference Travel Award to present a paper at the 1st Asian Congress on ADHD in Seoul, Korea 2012
4. Student Travel Award to present a poster and an oral presentation at the 4th World Congress on ADHD in Milan, Italy 2013

Presentations

Oral presentation

- Ghosh M, Holman CD, Preen D. Does parental country of birth play a role in pharmacotherapy for Attention Deficit Hyperactivity Disorder (ADHD)? A Whole-Population Linked Data Study. 1st Asian Congress on ADHD 2012, 2-3 November 2012, Seoul, Korea (Appendix I).

Poster presentation

- Ghosh M, Holman CD, Preen D. Explaining Ethnic Differences in the Use of Stimulant Medications for ADHD: A Whole-Population Study. 4th World Congress on ADHD: From Childhood to Adult Disease, 6-9 June, 2013, Milan, Italy (Appendix II).
This thesis contains the following published work and work prepared for publication, which have been co-authored.


2.1. Additional Table: Mean age in years at initial prescription in those receiving a stimulant medication for ADHD according to racial and demographic factors (Appendix V).


3.1. Interview Guide (Appendix IX).

3.2. Demographic Questionnaire (Appendix X).

# Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal</td>
<td>An individual of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or a Torres Strait Islander. The term Aboriginal in this thesis encompasses both Aboriginal and Torres Strait Islander.</td>
</tr>
<tr>
<td>ADHD symptoms/behaviour</td>
<td>Characterized by symptoms of hyperactivity, impulsivity and inattention.</td>
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<td>Anglophonic</td>
<td>The term referred to native English speakers born in Australia (non-Aboriginal), Canada, Europe, New Zealand, or North America.</td>
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<tr>
<td>Authorised prescriber</td>
<td>A medical professional who is authorized to initiate treatment with stimulant medications in WA.</td>
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<tr>
<td>Cohort</td>
<td>A group of individuals being studied who have experienced the same event at a specified period in time.</td>
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<td>Comorbidity</td>
<td>When an individual has more than one disease/health/behaviour problem at the same time.</td>
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<tr>
<td>eHRAF World Cultures</td>
<td>An online database that contains ethnographic collections covering present and past aspects of cultural and social life.</td>
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<td>DSM</td>
<td>The Diagnostic and Statistical Manual of Mental Disorders, published by the American Psychiatric Association, offers a common language and standard criteria for the classification of mental disorders.</td>
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<tr>
<td>Confidence intervals</td>
<td>A statistical term describing a range (interval) of values within which we can be confident that the true value lies, usually because it has a 95% or higher chance of doing so.</td>
</tr>
<tr>
<td>HPNO</td>
<td>Similar to Anglophonic. The term referred to native English speakers born in Australia (non-Aboriginal), Canada, Europe, New Zealand, or North America.</td>
</tr>
<tr>
<td>ICD-10</td>
<td>The World Health Organization’s internationally accepted classification of disease and health related problem.</td>
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<tr>
<td>Intervention</td>
<td>An action taken by medical professionals, policy makers or</td>
</tr>
</tbody>
</table>
community members which intervenes to improve health and behaviour outcomes.

Morbidity
Refers to ill health in an individual and to levels of ill health in a population or group.

Notification of Treatment form
Notification of Treatment Using Stimulant Medication Form. Submitted to the Department of Health by Authorised Prescribers when initiating, modifying or terminating treatment with stimulant medication in WA.

LPNO
Term applied to non-English speakers born in Africa, Asia, Middle East or South America.

Non-Anglophonic
Term applied to non-English speakers born in Africa, Asia, Middle East or South America.

Mortality
Death.

Prescription stimulants
Such as Ritalin or Adderall only prescribed by a registered medical practitioner and available from pharmacies only.

Prevalence
The number of cases present in a population at a given time.

Risk factor
A characteristic that is known to be associated with or causes a health related condition.

Statistical significance
An indication from a statistical test that an observed difference or association may be significant or real because it is unlikely to be due just to chance. A statistical result is usually said to be significant at the 5% level if it would occur by chance only once in twenty times or less.

WADLS
WADLS links administrative health data related to the same person from various different sources for the entire WA population. The WADLS is currently funded by the DoHWA.
<table>
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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
</tr>
<tr>
<td>ADHD</td>
<td>Attention Deficit/Hyperactivity Disorder</td>
</tr>
<tr>
<td>ARIA</td>
<td>Accessibility/Remoteness Index of Australia</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Intervals</td>
</tr>
<tr>
<td>DoHWA</td>
<td>Department of Health Western Australia</td>
</tr>
<tr>
<td>HMDC</td>
<td>Hospital Morbidity Data Collection</td>
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<tr>
<td>HPNO</td>
<td>Higher Propensity National Origin</td>
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<tr>
<td>HR</td>
<td>Hazard Ratio</td>
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<tr>
<td>eHRAF</td>
<td>electronic Human Relations Area Files</td>
</tr>
<tr>
<td>HREC</td>
<td>Human Research Ethics Committee</td>
</tr>
<tr>
<td>ICD-10</td>
<td>International Classification of Diseases – version 10</td>
</tr>
<tr>
<td>IRSD</td>
<td>Index of Relative Socio-Economic Disadvantage</td>
</tr>
<tr>
<td>LPNO</td>
<td>Lower Propensity National Origin</td>
</tr>
<tr>
<td>MNS</td>
<td>Midwives Notification System</td>
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<tr>
<td>MODDS</td>
<td>Monitoring of Drugs of Dependence System</td>
</tr>
<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
</tr>
<tr>
<td>OR</td>
<td>Odds Ratio</td>
</tr>
<tr>
<td>SD</td>
<td>Standard Deviation</td>
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<td>SEIFA</td>
<td>Socio Economic Indexes for Areas</td>
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<tr>
<td>SES</td>
<td>Socioeconomic status</td>
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<tr>
<td>SPH</td>
<td>School of Population Health</td>
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<tr>
<td>SPSS</td>
<td>Statistical Package for Social Science</td>
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<tr>
<td>UMRN</td>
<td>Unit Medical Record Number</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
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<tr>
<td>USA</td>
<td>United States of America</td>
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<tr>
<td>UWA</td>
<td>University of Western Australia</td>
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<td>WA</td>
<td>Western Australia</td>
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<tr>
<td>WAAHEC</td>
<td>WA Aboriginal Health Ethics Committee</td>
</tr>
<tr>
<td>WADLS</td>
<td>WA Data Linkage System</td>
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<tr>
<td>WAFCGS</td>
<td>WA Family Connections Genealogical System</td>
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</table>
CHAPTER 1

INTRODUCTION

1.1 OVERVIEW OF ADHD

Attention Deficit Hyperactivity Disorder (ADHD) is a commonly diagnosed chronic behavioural disorder in children and adolescents. The biomedical construct of ADHD is based on the theory that a child with ADHD suffers from a physiological brain disorder in one or more of the areas of attention, activity levels and impulsive behaviour, which in turn form the core diagnostic features. According to this theory, ADHD can be associated with significant educational and social impairment, and if not diagnosed, ADHD can be observed to persist into adulthood resulting in depression, functional impairment and reduced quality of life.

Under a social construct of ADHD, however, the features of the condition are perhaps better understood as a description of behaviours that do not conform to expected social norms. The common argument against the biomedical model of ADHD asserts that the diagnosis is not based on specific cognitive or neurological markers or clinical tests, but instead relies on a subjective interpretation that creates considerable uncertainty. The proponents of this theory argue that the ADHD label is the product of many factors in modern western culture that adversely affect the mental health of children and their families. Other scholars suggest that biological, psychological and social factors are all at play in the ADHD condition and advocate for an integrated biopsychosocial approach to its diagnosis and management.

1.2 USE OF STIMULANT MEDICATION FOR ADHD

Psychostimulant medication which is recommended as a first-line modality for ADHD treatment, is often the prime reason for the debate regarding the aetiology of ADHD, given further impetus by increasingly high rates of prescribing of psychostimulant medications for the treatment of ADHD in Western nations since the 1980s. Australia has followed the upward trend with a prescribing rate that increased by 26% per year from 1984 to 2000, and a further 72% total increase between 2000 and
2011. Australia now ranks third in the world in psychostimulant use after the USA and Canada. In Western Australia (WA), from 1989 to 2000, there was a 85%-90% increase in the prescribing rate, being historically the highest level of stimulant use of any Australian state. The rate declined by one-third between 2004 and 2010 following the introduction of the Stimulant Regulatory Scheme in mid-2003. The upward trend then recommenced with a 6% increase from 2010 to 2011, and a further 7.5% increase from 2011 to 2012.

The total direct annual national cost of ADHD in the USA in 2010 was estimated to be as much as US$143 to US$266 billion in the form of adult healthcare, productivity and income losses, and healthcare and education costs for children and adolescents. In Australia, the specific economic burden of ADHD has not been investigated separately from mental disorders. However, given the increasing rate of stimulant use has been surpassed only by the USA and Canada, one can assume that a similar economic burden of ADHD in Australia as observed in the USA. There is evidence supporting the effectiveness of stimulant medications in reducing ADHD symptoms. However, there is a significant concern regarding the side-effects of stimulants, the risk of long-term dependence, misuse and abuse and cardiovascular complications.

Despite the constant rise in the use of stimulant medications, there is a large variation in the prevalence of stimulant treatment for ADHD. Variations have been observed according to type and number of clinicians, socioeconomic status, geographic location, gender differences, family structure and parental education. Only a handful of studies of ethnic minorities in the USA have reported sociocultural variations in stimulant use in relation to health insurance, individual and institutional racism, disparities in healthcare access, family characteristics, English-language proficiency and socioeconomic status. There is a paucity of research explaining the sociocultural variations in stimulant use due to differences in beliefs and perceptions of ADHD behaviour and stimulant medications. Studies that investigated the differences in sociocultural beliefs about ADHD and stimulant use were conducted in the USA including only African-Americans, Hispanic-Americans and White-Americans. While ADHD symptoms and behaviours can be found in all human cultures, how these symptoms and behaviours are interpreted in terms of normality versus pathology largely depends on individual sociocultural beliefs and perceptions of health and illness, which in turn influence the individual’s health care seeking behaviour and...
their decision making about management of the condition. As such, it is critical to determine if disparities exist between cultural and racial groups in the use of stimulant medications and the factors associated with those disparities. To date, no research has been performed in an Australian setting focusing on sociocultural aspects of stimulant treatment for ADHD in either children or adults.

1.3 RATIONALE FOR THESIS

Australia has become a culturally and linguistically diverse nation with 28% of its population born overseas. Among the Australian jurisdictions, WA has the highest proportion of overseas born residents, and has the third largest Aboriginal population. Sociocultural and racial disparities in the prescription of stimulant medication for ADHD is not yet recognised as a major public health issue in Australia, even though lower utilisation rates of mental health services by immigrants, refugees, and Aboriginals have been observed. The findings from this thesis will provide the first population-based longitudinal study, on sociocultural and racial variations in prescription stimulant medication use for ADHD treatment in WA, in an attempt to identify variations and uncover some possible explanations of underlying factors. Cross-cultural comparisons may lead eventually to a deeper understanding of the social forces that have led to the rapid rise in the use of stimulants over the last decade. The information gained may provide insights for policy development to promote rational use of stimulant medications for ADHD as well as to address its future impact on the health of the Australian population. Further, the information may be pertinent to improving knowledge of cultural aspects within certain ethnic groups to better facilitate the objectivity of the diagnosis of ADHD, to improve the relationship between clinicians and individuals with ADHD and to provide socio-culturally appropriate services.

The WA Data Linkage System (WADLS) routinely links statutory administrative data from over 40 health services and research databases for the entire population of WA. The WADLS has provided valuable population-based data for epidemiological and health services research in the national priority area of mental and behavioural health. Further, the WA Family Connection Genealogical System (WAFCGS) of the WADLS has provided researchers with an unprecedented opportunity to facilitate familial risk assessments in cancer and other genetic diseases in WA. The ability of the WAFCGS to identify pedigrees with reasonable accuracy also has good potential to evaluate
sociocultural effects on health care, and in the case of this thesis, stimulant medications for ADHD.

1.4 AIMS OF THESIS

The aim of this thesis is to delineate the different patterns of stimulant medication use for ADHD treatment in WA according to sociocultural factors. The specific thesis objectives are to:

1. investigate parental country of birth differences in the use of stimulant medication for ADHD in WA;
2. investigate the pattern of stimulant use for ADHD in Aboriginal people in WA;
3. validate the association between country of birth and disparities in the prescription stimulant use for ADHD treatment in WA children and young adults; and
4. explore individuals’ perceptions of ADHD behaviour, the meaning that the diagnosis carries for them and their attitudes to stimulant treatment.

1.5 RESEARCH APPROACH

To achieve the research aims, the thesis has been divided into two parts: Part A and Part B. Part A was the primary phase comprising a quantitative comparison of use of stimulant medications by country of birth and race in WA using whole-population linked prescribing and dispensing stimulant data, and involving two retrospective cohort studies. The first cohort included all individuals born in WA from 1980 to 2007 for whom records of both country of birth and race were available in the WA linked data collections for both their mother and father. The individuals were then followed through links to the Monitoring of Drug of Dependence System (MODDS) between 2003 and 2007 to identify any stimulant medications treatment record for ADHD. The cohort for this study was selected from the WA Birth Registry and was linked to WAFCGS for parental ascertainment. The second cohort consisted of all individuals first admitted into a hospital in WA for any reason in the first 25 years of life between 1980 and 2007. Similar to the first cohort, the second cohort was also followed through links to the MODDS from 2003 to 2007. This cohort was selected using the WA Hospital Morbidity Data Collection (HMDC).
The qualitative study set out to explore individual’s understanding of ADHD and attitude to stimulant treatment. The study investigated personal, social and contextual factors that laid behind individual’s decision to initiate stimulant medication for ADHD treatment.

1.6 SCOPE OF THESIS

The scope of Part A of the thesis was limited to individuals who were born in WA (the first cohort), and who were admitted into a WA hospital in their first 25 years of life (the second cohort) from 1980 to 2007, and were followed through to identify who had stimulant medication for ADHD between 2003 and 2007. Therefore, individuals who might have stimulant medication treatment at any time before 2003, but did not continue after 2003, were out of scope. The rationale for the defined observation period with stimulant treatment from 2003 was that the new Stimulant Regulatory Guidelines commenced for the prescribing of stimulant medication in WA in 200373-74. According to the guidelines, a Notification of Treatment Using Stimulant Medication Form must be submitted to the Department of Health WA (DoHWA) by an authorised prescriber, with a Stimulant Prescriber Number, at the initiation of stimulant medication treatment for each patient, or for changes in medication dose, medication type, medication form or if the treatment is ceased73-74. The previous guideline was based on ‘en-bloc’ authorisations for prescribers and did not collect adequate information to allow for detailed analysis of stimulant medication use in WA74.

The scope of Part B was limited to those who themselves were diagnosed or had dependent children diagnosed with ADHD; aged over 18 years; and were able to converse fluently in English. Inclusion of participants who could not converse in English fluently was out of scope because having interpreters during interviews were not feasible due to limited resources allocated to a doctoral candidate.

1.7 STRUCTURE OF THESIS

This thesis is comprised of 11 chapters and is divided into two parts. The chapters of the thesis are organized as follows (Figure 1).
internationally as well as cross-culturally. Further, the rationale for undertaking this research is also further developed.

Chapter 2 presents a critical review of the relevant literature on the theories of ADHD. The thesis does not favour one theory over another, but makes an attempt to outline the aetiological complexity entwined with cross-cultural perspective of ADHD inherent within the ADHD literature. The chapter then covers literature on the treatment of ADHD, use of stimulant medications across international, national, racial and ethnic groups. The impact of sociocultural understanding of ADHD on stimulant medication treatment then follows.

Chapter 3 contains an outline of the overall study design and describes the methods deployed during the quantitative and qualitative components of the research. Issues regarding data storage, security and ethical practice are also canvassed in this chapter.
Chapter 4 describes the methods employed for the quantitative research in Part A in more detail. This chapter explains the procedures for conducting the two retrospective cohort studies, including the background to the WADLS, study design, linked data sources, selection of study cohorts, variables and their measurements, and statistical analysis.

Chapters 5, 6 and 7 feature the analysis of data and presentation of results from the quantitative research. Chapter 5, entitled ‘Exploring parental country of birth differences in the use of psychostimulant medications for ADHD: a whole-population linked data study’, and Chapter 6, entitled ‘Use of prescription stimulant for ADHD in Aboriginal children and adolescents: a linked data cohort study’ present and discuss the findings from the first quantitative study. These studies have been unique in their ability to draw on the WA linked Birth Registrations, FCGS and MODDS data to provide the genealogical resources to identify parental country of birth and race to measure ethnic variations in psychostimulant treatment for ADHD. Chapter 7, entitled ‘Identifying cross-cultural variations in psychostimulant use for Attention Deficit Hyperactivity Disorder using linked data’, reports and discusses findings from the second quantitative study. This chapter examines individuals’ own country of birth rather than parental country of birth influences on stimulant use for ADHD. Chapter 7 further validates the methods and findings from quantitative study one in Chapter 5. Chapter 5, 6 and 7 are presented as manuscripts prepared for publication in peer reviewed journals. Chapter 5 and Chapter 7 have been published. Chapter 6 is currently under review. These chapters are presented as replications of the journal manuscripts, albeit formatted for the thesis.

Chapter 8 contains a summary of the key quantitative findings in Part A and connects them to Part B, the qualitative research. Chapter 9 deals with the qualitative research method and procedure through an exploration of theoretical frameworks, study design, sample size, data collection and data analysis. Chapter 10, entitled ‘It has to be fixed: a qualitative inquiry into the perceived ADHD behaviour’, presents the themes that arose from qualitative analysis. This chapter addresses how individuals from a traditionally Anglophonic background living in Perth perceived ADHD behaviour, the meaning that ADHD diagnosis carried for them and their attitudes to stimulant medication treatment. Chapter 10 has also been published and presented as a replication of the journal manuscript, albeit formatted for the thesis.
Chapter 11 incorporates the discussion and triangulation of thesis Part A quantitative and Part B qualitative key findings by examining whether the thesis has been successful in its original aims and objectives. The chapter highlights strengths and limitations of the thesis and offers a view on priorities for future research. The implications of the thesis in terms of policy and practice related to ADHD and stimulant medication treatment are discussed. The chapter concludes with a summary of the key findings and significance of the thesis.

In this thesis the term ‘Anglophonic’ has been used to refer to individuals or their parents born in Australia including New Zealand, Europe or North America including Canada, and has been alternatively referred to ‘Higher Propensity National Origin’ (HPNO). Individuals or parents born in Africa, Asia, the Middle East or South American countries have been referred to ‘non-Anglophonic’, a term used interchangeably with ‘Lower Propensity National Origin’ (LPNO). The author appreciates that the use of Anglophonic and non-Anglophonic do not represent exactly what languages individuals speak, but rather a set of complex distinctions between two sets of nations in the world, one dimension of which is a strong tendency for the HPNO nations to either speak English as their national language or to learn English as a second language from a young age. This basis for the distinction is by no means complete or strictly accurate and the use of the terms is somewhat motivated by the need for a convenient shorthand.

The term ‘Aboriginal’ encompasses both Aboriginal and Torres Strait Islanders. The terms ‘stimulant medication’, ‘stimulants’, ‘psychotropic drug’ or ‘psychostimulant medication’ for ADHD treatment have all been used interchangeably.
CHAPTER 2

LITERATURE LANDSCAPE

2.1. INTRODUCTION

As outlined in Chapter 1, the overarching aim of the thesis was to explore the disparities in the utilisation of prescription stimulant medication for treatment of ADHD in Western Australia with an understanding of sociocultural perceptions of ADHD diagnosis and medication treatment. In this chapter I provide an outline of the nature, theories and treatment of ADHD through a detailed review of the available research literature. The literature review begins with a description of the conventional medical approach to the understanding of ADHD, as well as the prevalence and co-occurring conditions associated with ADHD. Other prominent theories to which ADHD is linked are then discussed. The goal of this chapter is not to provide an exhaustive account of every theory about ADHD; but rather to summarise the key theories and to recognise that ADHD is a complex issue. It is not the intention to answer all of the questions associated with ADHD, nor to advocate one theory above another. Neither is the legitimacy of the ADHD condition or the effectiveness of stimulant medication for ADHD treatment questioned. Rather, in this chapter I acknowledge the pertinent aspects to this thesis of the phenomenon known as ADHD, which may have considerable impact on variations in stimulant treatment use in Australia. Sociocultural beliefs and understandings of the aetiology of ADHD and stimulant treatment have been examined in detail. Cultural groups, with a focus toward racial and ethnic groups, are identified using broad descriptions. The utilisation of stimulant medication for ADHD treatment across racial and ethnic groups has been explored followed by a review of the impact of cultural understanding of ADHD on treatment-seeking behaviour.

2.2. METHODOLOGY FOR LITERATURE SEARCH

A literature review was conducted using the AUSTHEALTH, EMBASE, MEDLINE, OVID, PUBMED and ProQuest, bibliographical research databases by searching the following MeSH (Medical Subject Headings) terms in table 1. Related links to cited articles were also reviewed. Searches were also performed for studies undertaken by
the Department of Health Western Australia (DoHWA) and the Australian Psychological Society.

Table 1. MeSH terms in literature search

<table>
<thead>
<tr>
<th>ADHD</th>
<th>Behavioural problems</th>
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<tr>
<td>Attention deficit</td>
<td>Behavioural disorder</td>
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<td>ADHD and cost</td>
<td>Culture and ADHD behaviour</td>
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<td>ADHD and environment</td>
<td>Developmental disorders</td>
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<td>ADHD and epidemiology</td>
<td>Drug therapy</td>
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<td>ADHD and comorbidities</td>
<td>DSM IV</td>
</tr>
<tr>
<td>ADHD and culture</td>
<td>DSM V</td>
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<td>ADHD and genetic</td>
<td>Aetiology of ADHD</td>
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<td>ADHD and gender</td>
<td>Family structure</td>
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<td>ADHD and misdiagnosis</td>
<td>Hyperkinetic disorder</td>
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<td>ADHD and rating</td>
<td>Hyperactivity</td>
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<tr>
<td>ADHD and referral</td>
<td>Impulsivity</td>
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<tr>
<td>ADHD and socioeconomic status</td>
<td>Inattention</td>
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<tr>
<td>ADHD behaviour therapy</td>
<td>Pharmacotherapy</td>
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<tr>
<td>ADHD behaviour rating scale</td>
<td>Pharmaco-epidemiology</td>
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<tr>
<td>ADHD risk factors</td>
<td>Prescription stimulant</td>
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<tr>
<td>ADHD symptoms</td>
<td>Psychosocial treatments</td>
</tr>
<tr>
<td>ADHD in children</td>
<td>Stimulant medication</td>
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<tr>
<td>ADHD in adults</td>
<td>Temperament</td>
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</table>

Reviewed literature containing information about epidemiology, prevalence, diagnosis of ADHD, as well as belief and perception of ADHD behaviour in cross-cultural settings included:

- Peer-reviewed journals dedicated to epidemiology, child psychiatry, behavioural disorders, cross-cultural psychiatry and pharmacotherapy.
- Reports generated from the Pharmaceutical Services Branch, DoHWA.
- Reference lists of key articles cited provided another source of pertinent reports.
- Current updates of publications and abstracts from the World Congress on ADHD, Asian Congress on ADHD and from major scientific meetings.

The search strategy included literature up until 30 June 2015 with a focus on literature since 1990, but with landmark studies prior to 1990 also being included.
2.3. WHAT IS ADHD?

The answer to the question “What is ADHD?” arguably depends on the perspective of the person to whom the question is posed. In medical terms ADHD “is a heterogeneous behavioural syndrome characterised by the core symptoms of hyperactivity, impulsivity and inattention”\(^3\). ADHD represents the most common childhood behavioural symptoms which was first defined as a mental disorder in the Diagnostic and Statistical Manual of Mental Disorder 3\textsuperscript{rd} edition (DSM-III)\(^7\). The current edition of that manual (DSM-V), released in May 2013, describes ADHD as a neurodevelopmental disorder characterised by age-inappropriate levels of inattention and hyperactivity-impulsivity, and identifies three subtypes: i) Predominantly Inattentive Presentation (ADHD-I), ii) Predominantly Hyperactive-Impulsive Presentation (ADHD-H), and iii) Combined Presentation (ADHD-C)\(^2\). According to the DSM-V there are 18 ADHD symptoms as follows:

**Inattention:**

1) Often fails to give close attention to details or makes careless mistakes in schoolwork, at work, or with other activities.
2) Often has trouble holding attention on tasks or play activities.
3) Often does not seem to listen when spoken to directly.
4) Often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (e.g., loses focus, side-tracked).
5) Often has trouble organising tasks and activities.
6) Often avoids, dislikes, or is reluctant to do tasks that require mental effort over a long period of time (such as schoolwork or homework).
7) Often loses things necessary for tasks and activities (e.g. school materials, pencils, books, tools, wallets, keys, paperwork, eyeglasses, mobile telephones).
8) Is often easily distracted.
9) Is often forgetful in daily activities.

**Hyperactivity:**

1) Often fidgets with, or taps hands or feet, or squirms in seat.
2) Often leaves seat in situations when remaining seated is expected.
3) Often runs about or climbs in situations where it is not appropriate (adolescents or adults may be limited to feeling restless).
4) Often unable to play or take part in leisure activities quietly.
5) Is often "on the go" acting as if "driven by a motor".
6) Often talks excessively.

Impulsivity:
7) Often blurts out an answer before a question has been completed.
8) Often has trouble waiting his/her turn.
9) Often interrupts or intrudes on others (e.g., butts into conversations or games)

A diagnosis of ADHD is largely based on observations of six or more of the above symptoms in children up to age 16 years, or five for adolescents aged 17 years or older, which are persistent for at least six months to a degree that is maladaptive and inappropriate for the individual’s developmental level. The age of first onset of the symptoms has been extended from seven years in the DSM-IV to 12 years in the DSM-V. The average onset of the symptoms is reported at 3-4 years old, although one half of all ADHD cases develop by age seven years, while 93% develop by 12 years of age and more than 98% by age 16 years. Early observational studies of the developmental course suggested that ADHD symptoms persist into early to late adolescence in about 50%-80% of children with ADHD; and into adulthood in about 66% of original cases.

2.4. PREVALENCE OF ADHD

Prevalence estimates for ADHD vary throughout the scientific literature. This is likely due to the prevalence of ADHD largely depending on the diagnostic measures, population characteristics, study methodologies, clinical practices, ethnicity, location, age and sex of the study population. Inconsistencies in the diagnostic tools have influenced a wide range of reported ADHD prevalence from 2.2% to 17.8%. Some population-based epidemiological studies have even reported that more than 31% of children evaluated by their parents and teachers had ADHD, although it is perhaps not surprising that estimates from these evaluators would differ from clinically trained specialists. Based on parent-report data, the US Centers for Disease Control suggested that ADHD affected about 1 in 10 children, and that the life time prevalence of ADHD diagnosis had increased by 22% between 2003–2007. Similarly, ADHD outpatient visits had reportedly increased by 68% from 6.2 million to 10.4 million during 2000–
2010. A recent study showed that extending the age-of-onset criterion from 7 to 12 years in the DSM-V led to an increase in the prevalence by 7.4% to 10.8% in the US. The worldwide-pooled prevalence of ADHD has been estimated between 5.3% to 7.2%. Prevalence of ADHD in ethnic minorities has not been well established to date; however, cross-cultural studies suggest that ADHD exists worldwide with international prevalence rates similar to those reported in the US. The highest prevalence of clinically diagnosed ADHD in children was reported in India at 29%, and the lowest was documented in Ethiopia at 1.5%.

In Australia, prevalence estimates have ranged from 1.6% to 11%, with boys far more likely to receive a diagnosis of ADHD than girls in a ratio of 5:1. In one study the Australian childhood community prevalence was about 6.8%, being similar to that reported worldwide. For adults the worldwide prevalence is approximately 2%. Among Australian adults, the lifetime prevalence of ADHD was reported as 0.9% in women, and 2.1% in men. The differences in prevalence of ADHD raise a question as to whether there has been sufficient compliance with standard guidelines for ADHD recognition outlined in the DSM-V. Alternatively, the differences in prevalence may underline the importance of identifying possible variations in risk factors or gaps in the diagnostic identification of ADHD, particularly across different cultural groups.

2.5. COMORBIDITIES

Individuals with ADHD are considered at increased risk of a variety of other psychological and developmental disorders. It is estimated that about 87% of clinically diagnosed ADHD children have at least one other disorder and 67% have at least two or more other disorders besides their ADHD. For adults, more than 80% have at least one or more, and more than 50% have two or more additional mental disorders. The most common comorbid conditions include oppositional defiant disorder, conduct disorder, antisocial disorder, anxiety, mood disorder, learning disabilities, motor tic disorder and Tourette syndrome.

Research shows that up to 35% of ADHD children and adolescents suffer from oppositional defiant or conduct disorders, depression and mood disorders coexistent with ADHD in 18%, and an anxiety disorder coexists in 25% of children and adolescents. According to one source the coexistence of ADHD and learning
disabilities in children ranged from 12% to 60%\textsuperscript{109}. The coexistence of ADHD with conduct disorder in adults is reported at about 26%, while depression occurred in 14\%\textsuperscript{5}. Up to 18% of children may develop a motor tic in childhood that declines to a about 2% by mid-adolescence and less than 1% by adulthood\textsuperscript{110}, while the risk of motor tics in children with ADHD is about 20\%\textsuperscript{111}. It is recommended to preclude some comorbid conditions when the problem is better explained by another diagnosis category, such as autism or bipolar disorder\textsuperscript{100}.

2.6. OUTCOMES OF ADHD

Educational and academic difficulties are the most common adverse outcomes that children and young people with ADHD experience\textsuperscript{6}. In addition, children with ADHD have been observed to make higher use of support services and placements in special education classes\textsuperscript{6}. Quality of life has been studied from the parents’ perspective with the conclusion that the presence of ADHD symptoms has a significant negative impact on quality of life\textsuperscript{112}. Bussing\textsuperscript{113} observed that adolescents with childhood impulsive ADHD were more likely to experience depression, functional impairment, reduced quality of life and involvement with the juvenile justice system, while those with inattentive ADHD had an increased risk of academic failure. Based on the potential for persistence of ADHD into adulthood, a recent systematic review which summarised findings from 351 studies assessing long-term outcomes of treatment and non-treatment of ADHD\textsuperscript{8}, found that untreated ADHD to be significantly associated with a higher likelihood of poorer long-term outcomes in nine major categories: academic, antisocial behaviour, driving, non-medicinal drug use/addictive behaviour, obesity, occupation, services use, self-esteem, and social function.

2.7. ECONOMIC BURDEN

Despite global attention and the concern surrounding the increased use of ADHD medications, there has been only limited analysis of the economic burden of ADHD, predominantly conducted in US. In 2010, the total annual national cost of ADHD was estimated to be between $143 and $266 billion\textsuperscript{28}. Reviewing 13 studies on the economic costs of ADHD, Pelham et al.\textsuperscript{114} noted that the annual estimated costs ranged from US$12,005 to US$17,458 per individual. The costs arose from medical care, special education, disciplinary processes, parental work loss and juvenile justice. Using a prevalence of 5\%, they estimated the annual economic cost of ADHD in the US was
between US$36 and US$52 billion, with additional incurred costs of US$503-1,343 for a child with ADHD, and US$4,929-$5,651 for an adult with ADHD\textsuperscript{115}. Indirect costs of ADHD associated with a loss of productivity in the workplace were estimated at 143.8 million days each year in the 10 surveyed countries from North and South America, Europe and the Middle East\textsuperscript{116}. In a systematic review, the average total cost in European countries ranged from €9,860 to €14,483 per patient and the annual national costs were between €1,041 and €1,529 million in 2012\textsuperscript{117}. The costs included ADHD-related education and healthcare costs for ADHD children and adolescents and their family members, productivity losses of the family members and social services cost. Worldwide, the estimated expenditure increased from US$720 million in 1999 to US$2.4 billion in 2003 with an increase of 579\% in real terms\textsuperscript{118}. In many developing countries including the US, Canada and Australia annual spending growth on ADHD medications exceeded 20\% over the past decade\textsuperscript{119}.

In Australia, the economic burden of ADHD alone has not been investigated but was partially examined through investigation of overarching mental illness. In 2008, the economic cost of mental illness which included ADHD in the community totalled $5.32 billion, representing 7.5\% of all government health spending, reflecting the cost of operating the mental health service system only, and excluding another $4.63 billion spent in other support services such as income support, housing assistance, domiciliary care and employment opportunities\textsuperscript{120}. It was also suggested that individuals’ personal costs, and other indirect costs such as lost productivity and costs to non-government organisations were at least equal to if not more than government expenditures. Stimulant medication dose was measured and reported from New South Wales, where there were 5.015mg “defined daily doses” per 1,000 population per day for 4–17 year old children and adolescents in 2006\textsuperscript{100}, while in Western Australia, the average daily notified doses in 2004 and 2012 respectively were recorded as 17.4mg and 15.9mg in children, and 33.8mg and 32.1mg in adults\textsuperscript{27}.

2.8. AETIOLOGICAL CONTROVERSY WITH ADHD

Although there is a great amount of research being conducted in the area of ADHD, the aetiology and diagnosis of the condition persist as points for significant social and scientific debate. A possible driver for this debate is the fact that healthy children aged under five years often display behavioural characteristics that include features
analogous to the symptoms of ADHD, such as hyperactivity and inattentiveness\textsuperscript{121}, but these children might not necessarily be suffering from a disorder. As mentioned earlier, multiple theoretical models have been proposed to explain the development of ADHD, because ADHD is a complex phenomenon which can be understood and interpreted in different ways\textsuperscript{122}.

2.8.1. ADHD – a neurological condition

One of the dominant theories in the literature suggests that ADHD is a neurological condition; effectively a neurological deficit in response to inhibition that leads to impairments in executive functions, such as working memory, self-regulation, internalisation of speech, planning and motor behaviour\textsuperscript{123}. Willcutt and colleagues\textsuperscript{124} conducted a meta-analysis of research that revealed significant differences between ADHD and control groups in all areas of executive function, leading the researchers to conclude that no single area of deficit alone is the cause of ADHD. To examine the underlying physical causes of ADHD, researchers employed neuro-imaging technologies using high-resolution magnetic resonance imaging devices to more accurately determine the specific areas of the brain underlying ADHD. Studies employing this technology found functional abnormalities in dopamine transmission in the brain of people with ADHD\textsuperscript{125-126}, leading to further postulation of a neurobiological aetiology of ADHD. These studies, whilst indicating the co-occurrence of structural and chemical disruptions in the brain of people with ADHD, have not yet been able to demonstrate a clear causal link between structural brain abnormalities and ADHD. The evidence for neurobiological explanations has been further criticised for its lack of longitudinal data, uniformity in brain pattern within ADHD sufferers, and research limited to a small percentage of the general population\textsuperscript{127-128}. Conducting a literature review on brain research on ADHD, Doggett\textsuperscript{128} concluded, “while ADHD brains are different, they also have many of the same developmental and neurological features as other types of brains … therefore, scientists cannot agree with certainty that ADHD children have a unique and identifiable brain blueprint” (p.74).

2.8.2. ADHD – a genetic condition

This biomedical construct of ADHD relies on a purported genetic aetiology of ADHD in order to understand the nature of the condition. The supporters of this theory advocate that ADHD is a highly heritable condition, and either genetic variants or
genomic regions play a significant role in the development and course of ADHD\textsuperscript{5,129}. Biederman and colleagues found that about 10-35\% of the immediate family members of ADHD children were likely to have ADHD, with the risk to siblings of the ADHD children being approximately 32\%\textsuperscript{130}, and even the risk to the offspring of parents with ADHD was 57\%\textsuperscript{131}. Some studies have used molecular genetic techniques to analyse DNA (Deoxyribonucleic acid) taken from ADHD children and their family members to identify individual candidate genes as the basis for a genetic aetiology of ADHD\textsuperscript{132-133}. However, many researchers do not support a principal role of genetic factors and caution that pursuing a genetic basis may limit further exploration of psychological causes\textsuperscript{134}. Despite this argument, results from twin studies have indicated that ADHD has a heritability of 75\%\textsuperscript{107}. In another study, parents of ADHD children compared with control parents were reported to have high levels of inattention, cognitive problems, hyperactivity, impulsivity and low level of self-concept\textsuperscript{135}. In the same study, however, no difference was found in those symptoms between biological and non-biological parents of ADHD children. This finding supports the concept of familiar aggregation, by which the apparent heritable factor was, at least partially, due to the environment and social learning.

2.8.3. ADHD – an environmental condition

One of the environmental theories of ADHD that has been proposed, but not received much support, has been the quality of parenting. The theory conjectured that the hyperactive behaviour was the result of lack of caring for and managing the child in early elementary years\textsuperscript{136}. Further, a dysfunctional discipline style in parents has been shown to be predictive of childhood ADHD persistent into adulthood\textsuperscript{137-138}. Parental psychological problems are also claimed to be a strong predictor for development and persistence of ADHD\textsuperscript{139}. A recent systematic review, focusing on the relationship between parenting and functional impairments, showed that ADHD was associated with greater stress within the family, higher rates of parental psychopathology and conflicted parent-child relationships\textsuperscript{140}.

Other environmental factors that seem to have relevance to the aetiology of ADHD include low socioeconomic status\textsuperscript{141}, smoking during pregnancy and low birth weight\textsuperscript{142}, premature delivery\textsuperscript{143}, maternal mental health problems and foster care placement\textsuperscript{127}, older maternal age\textsuperscript{144} and a parental history of antisocial behaviour\textsuperscript{145}. 

17
Specific environmental toxin exposures such as lead and polychlorinated biphenyls appear to have a consistent and statistically significant relationship with the development of ADHD symptoms. Eubig and colleague\textsuperscript{146} in a review of both human and animal studies examining the effects of lead and polychlorinated biphenyl exposures on cognitive abilities and behaviour outcomes similar to those affected in ADHD children, reported evidence of impairments in working memory, response inhibition, vigilance and alertness. They further reported that even low-level lead exposure was associated with a clinical diagnosis of ADHD. Some dietary patterns have been reported to be associated with an increase in ADHD diagnosis in a longitudinal study in Western Australia, where the researcher observed that a “Western style diet” with higher levels of total fat, saturated fat, refined sugars and sodium was a strong predictor of ADHD\textsuperscript{147}. However, evidence for a causal link between dietary patterns and ADHD is inconsistent across studies, and the quality of studies is limited by small sample sizes, subjective outcome measures, non-standardised intervention protocols and the considerable potential for confounding\textsuperscript{148}. Thapar et al.\textsuperscript{149} concluded that more research is required to establish the significance of environmental toxins or dietary patterns as possible causes of ADHD.

\textbf{2.8.4. ADHD – a biopsychosocial condition}

Other scholars have proposed that biological factors interact with psychosocial factors in the individuals’ social, cultural and physical environment, which in turn leads to individuals’ behavioural manifestations of ADHD. Thus, they describe ADHD as a biopsychosocial condition\textsuperscript{17,122,150}. This model dismisses the concept of ADHD as an entirely social construction and proposes rather that biological elements interact with psychosocial factors in the individual’s environment. According to the model the development of ADHD arises from a complex interaction between individual biological factors and contextual factors within the environment. This theory suggests that environmental influences play a critical role in driving the manifestation of ADHD in the presence of certain biological susceptibilities. Thapar et al.\textsuperscript{149} concluded that environmental factors contributed to the development of the disorder and associated emotional, behavioural and academic difficulties. This interactive model has enjoyed increasing popularity in recent years; however, critics argue that despite the possibility that biological, psychological and social elements may influence each other, they may not equally contribute to each type of ADHD behaviour\textsuperscript{151}. Furthermore the model does
not address cultural factors in ADHD or structural barriers to treatment choice that families may encounter. A more comprehensive biopsychosocial-cultural model has been proposed to address cultural factors. This model is underpinned by the biopsychosocial model, and is based on two basic assumptions: (a) an individual’s level of functioning is multifactorial in nature and reflects the individual’s attempt to cope with stressors within their environment; and (b) treatment is tailored to the individual child or family and takes account of biological, psychological and socio-cultural factors that affect the likelihood of treatment acceptability. Consequently the scholars of this school advocate for an integrated biopsychosocial approach to ADHD diagnosis and its management.

2.8.5. ADHD – a socially constructed illness

There has been considerable debate questioning whether ADHD is a real disease such as a neuro-genetic condition or a socially constructed illness. The latter argument is that ADHD is used to label children who are not ill, but whose behaviour is at the extreme end of the normal range. The argument goes on to say that a consistent genetic marker has not been identified and neuroimaging studies have been unable to identify a unique aetiology for ADHD. Thus, concerns have been raised that “ADHD is not a disease per se but rather a group of symptoms representing a final common behavioural pathway for a gamut of emotional, psychological and/or learning problems” (p. 994). The lack of evidence of a unique genetic, biological or neurological pathology hinders the general acceptance of ADHD as a neurobehavioural disease entity. Under this social construct of ADHD, the features of the condition are better understood as a description of behaviours that do not conform to expected social norms. The proponents of this theory argue that the ADHD label is the product of many factors in modern western culture that adversely affect the mental health of children and their families. The controversy surrounding the notion of ADHD leads others to reject the existence of ADHD as a ‘true objective disorder’, and instead to accept that ADHD is socially constructed as a result of the pressures and vogues of modern society.

2.9. CULTURAL PERCEPTIONS OF THE AETIOLOGY OF ADHD

Some uncertainty about the aetiology of ADHD has been noted during the review of the literature set out above. It is therefore of little surprise that diverse cultural groups have their own distinct perceptions of the causes of ADHD. These cultural understandings
have been influenced by certain facts: ADHD affects more males than females\textsuperscript{155}, and the most disadvantaged more so than the least disadvantaged\textsuperscript{47,156}. In addition, the diagnosis of, and stimulant treatment for ADHD are on the rise. ADHD is chronic and often co-exists with a number of other psychiatric conditions\textsuperscript{4}. Another fact is that there is no complete cure.

Research has indicated that a lower prevalence of ADHD exists in ethnic minorities in the USA, and this lower occurrence has been linked to cultural differences in assessment and reporting of child symptoms by informants\textsuperscript{47,157}. Whilst it is agreed that individual beliefs about the aetiology of ADHD influence help-seeking behaviours\textsuperscript{65}, only a few researchers have investigated how people from different cultural backgrounds perceive symptoms of ADHD, their beliefs about the causes of ADHD, and how their perceptions influence the course of treatment. To examine parental beliefs about the causes of ADHD and its impact on treatment choice, Johnston et al.\textsuperscript{158} conducted telephone interviews in Canada. They reported that the parents, most of who were White European Canadians, believed that biological and genetic causal factors lay beneath their children’s ADHD behaviours, thus suggesting a disease perspective on ADHD. Similar to that, Pham et al.\textsuperscript{159} explored cultural differences in parental beliefs in the USA about ADHD where the participants were predominantly Caucasians, with few African-Americans and Latino-Americans in the study sample. The authors did not find any significant ethnic differences in beliefs. The causal explanations that the participants offered most frequently were based on a medical model of ADHD, such as ‘changes in brain activity’ or ‘neurological functioning’. However, some believed ADHD was influenced by parenting skills, lack of discipline and stress.

Parents’ beliefs and understandings of the cause of their child’s behavioural problems depend on cultural notions of the behaviour. Mexican-American and Puerto Rican parents were reported to place high value on behaviours that demonstrated responsibility, respect and compliance\textsuperscript{160}. This was consistent with the meaning of ADHD for Latino children, who described their ADHD in terms of “getting into trouble”\textsuperscript{161}. The Latino cultural values of family and traditional gender roles have been correlated with sociological and spiritual beliefs regarding the etiology of ADHD\textsuperscript{162}. Latino parents seem not to identify ADHD symptoms as a medical condition and do not sense the behaviours as problems that require mental health treatment\textsuperscript{163}. Rather, perceived disrespect is the main factor in how they evaluate and report their child’s
In another study\textsuperscript{165}, however, Latino immigrants to the USA accepted the biological perspective of ADHD and viewed their child’s behaviour as an illness. Acculturation played a significant role in Latino parents’ causal explanations of ADHD in this context. The immigrant families began to adopt the beliefs of the dominant Caucasian culture and accepted clinical perspectives on ADHD to explain their child’s problem. Nevertheless, the participants in the study often referred also to the traditional Latino culture as their “second culture”, and mentioned that their child’s ADHD behaviour was viewed as a lack of discipline and manners in their “second culture”. Debates regarding the validity of the construct of ADHD has been suggested to make African-American people ‘fearful’ about the diagnosis and treatment\textsuperscript{161}.

2.10. CULTURE AND DIAGNOSIS OF ADHD

Two main diagnostic criteria for ADHD are in current use: i) DSM-V published by the American Psychiatric Association\textsuperscript{2}, and the International Classification of Disease 10\textsuperscript{th} revision (ICD-10) published by World Health Organization\textsuperscript{166}. The DSM-V is predominantly used in North America and Canada, while the ICD-10 is used extensively in Europe\textsuperscript{3}. In Australia the DSM-V criteria are the minimum necessary for ADHD diagnosis\textsuperscript{100}. The ICD-10 criteria for hyperkinetic disorder include similar symptoms to the DSM-V as those described earlier in this chapter; however, unlike DSM-V, which employs a broader and more inclusive definition embracing a number of different ADHD subtypes, the ICD-10 is more restrictive and requires severe symptom expression, does not permit co-morbidity and excludes people with autism, anxiety and mood disorder\textsuperscript{3,100}. In either classification system the diagnostic criteria for ADHD require that both symptoms and impairment are observed in at least two settings, such as at home and in school. The observations are then documented and compared with the list of criteria appearing in the diagnosis manuals. During this process, it is common to have significant observer disagreement in the reported levels of severity, because determining severity of behaviour is a matter of observer and clinical judgment.

The diagnosis of ADHD, like the aetiology of ADHD, has not been without social and cultural debate. According to Singh\textsuperscript{13}, reliable diagnosis rates for ADHD are unlikely to be found because the methods to diagnose ADHD are not scientific. Although the biomedical model of ADHD suggests neurological dysfunction as the main cause of ADHD, there is currently no a specific cognitive, neurological marker or clinical test.
that can establish the existence of the disorder in an individual. Instead it relies on the observer’s interpretation of disruptive behaviour and thus creates a “zone of ambiguity” especially in the very young. For example, in an analysis of the levels of agreement between parents’ and teachers’ assessments of children’s ADHD symptoms, Papageorgiou et al. found that parents reported more hyperactivity and behavioural problems than teachers. In a community sample in the Netherlands, Rettew et al. examined parent-teacher disagreement and noted that parents reported clinical levels of problems when teachers did not and vice versa. They concluded that disagreement between informants was more the rule than the exception.

To estimate the prevalence of ADHD symptoms in Japanese children attending kindergarten or nursery school, Soma and colleagues conducted two surveys using a 14-item questionnaire based on DSM-III-R. The first survey was conducted in 2003 and involved school teachers to evaluate ADHD symptoms in 9,956 children. The second survey was conducted three years later in 2006, when parents evaluated ADHD symptoms in 7,566 children. The prevalence of ADHD in the teacher survey was 4.3%, while it was 31% in the parent survey. The authors concluded that parental evaluation of ADHD symptoms using DSM criteria might not be appropriate for ADHD screening. Disagreements in the level of reported problem behaviours could be due to a number of factors, including actual behaviour differences in the child across settings, memory and judgment differences by the informant, site differences in ability to elicit behaviour being assessed, candour of informants and measurement error.

Moreover, different cultural interpretations of normal behaviours may influence the ratings of observed behaviours, even when the same diagnostic criteria are applied. To compare diagnoses between England and the USA, Jacobson studied a group of 53 English children aged 10-11 years and found that those who were defined as “normal” in England, manifested the symptoms of ADHD as it was “labelled” in the USA. Mann et al. compared vignette ratings of clinicians from different cultures and reported that Chinese and Indonesian clinicians gave significantly higher scores for hyperactive-disruptive behaviours to the same videotape vignettes as compared with Japanese and American clinicians. Similarly, O’Leary et al. compared the diagnosis ratings between US and Italians clinicians, who scored similarly in diagnosing case descriptions. However, they differed significantly in the reported use of such assessments to diagnose ADHD in routine clinical practice. Wolraich and colleagues.
evaluated a measurement model of ADHD in a cross-cultural study, where elementary school teachers rated 21,161 children in four locations: Spain, Germany, urban (city-based) USA, and outer suburban USA. The authors found that the two factor model, namely inattention and hyperactivity, provided the best fit for all four samples in the two continents. Bird reported that even though the symptoms of ADHD were recognised by parents and clinicians, to what extent the behaviour was considered problematic and representing a pathological disorder depended on the norms of behaviour accepted in a particular culture\textsuperscript{174}. The ambiguity surrounding the diagnostic strategies thereby also led to questioning the ontological validity of the disorder\textsuperscript{15}.

2.11. CULTURAL DIFFERENCES IN INTERPRETATION OF EXTERNALISING BEHAVIOUR

ADHD symptoms like hyperactivity, impulsivity, disruptiveness and inattentiveness can be found in all children across cultures to some degree; however, how the symptoms are interpreted in different cultures can influence almost every aspect of the diagnostic and treatment processes\textsuperscript{175}. There is a dearth of research that investigates the interpretation of externalising behaviours of ADHD across cultures. In one study, Indian children with ADHD behaviours were most commonly described by their teachers as naughty, playful, mischievous, more active, less attentive and more curious and intelligent, with a belief that child’s mischievous behaviour would improve as a function of age\textsuperscript{176}. The maturational perspective in Indian society has been linked to a delay in ADHD diagnosis\textsuperscript{177}. Similarly, in Iranian culture, children’s externalising behaviours were interpreted as mischievous acts or a “natural behavioural stage of childhood development”\textsuperscript{178}.

There has been some research that examined perceived mental illness in the Muslim immigrant community of the USA. It reported that Muslims attributed mental health problems as arising from a lack of faith in God, spirit possession, bad karma or the evil eye\textsuperscript{179}. They felt that admitting mental health problem was a sign of weakness and having lost their faith in God as they believed that their religion was the source of healing and strength for mental health problems\textsuperscript{180}. As such, Muslims were encouraged to overcome mental health problem by becoming mentally stronger and tougher\textsuperscript{181}. There are no studies that specifically focus on ADHD in Native Americans. Ethnographic observations indicate that Native Americans value a connection between
mind, body, and spirit, and tend to relate any experience of mental illness through their worldview of connectedness to their total environment. Their construction of mental illness suggests that the Native Americans would not identify the ADHD symptom as a disorder, but rather as an imbalance in this connection. Due to the differences in cultural interpretation of ADHD behaviour, clinicians need to be aware of cultural influences on the diagnostic process in ADHD.

2.12. CULTURAL GUIDELINES IN DSM-V DIAGNOSTIC TOOL

In order to address the modification of diagnosis by culture and to guide appropriate identification of ADHD, the DSM-V cultural guidelines expect a “systematic review of the individual’s cultural background, the role of the cultural context in the expression and evaluation of symptoms and dysfunction, and the effect that cultural differences may have on the relationship between the individual and the clinician”2. The following categories are recommended in the DSM-V for reviewing cultural formulation:

a) Cultural identity of the individual – Noting the individual’s ethnic and cultural identity; degree to which the individual is involved with both the culture of origin and host countries; and language abilities, use and preference (including use of more than one language).

b) Cultural conceptualisations of distress – Identifying predominant idioms of distress used in explaining symptoms; the meaning and severity of the symptoms; perceived causes; explanation of the illness and experience with accessing care; and relationship with the professionals providing the care.

c) Psychosocial stressors and cultural features of vulnerability and resilience – Recognising culturally relevant interpretations of social stressors; available social supports; impacts of the child’s disability on the individual; and the family’s level of functioning and coping mechanisms.

The cultural formulation was set out for appropriate identification of ADHD in diverse cultural situations. Yet a wide cultural variation in the prevalence of ADHD diagnosis raises a concern as to the cultural validity of the diagnostic stool.

2.13. TREATMENT AND MANAGEMENT OF ADHD

It should be recognised that like the differences in diagnostic practices, recommendations for the treatment and management of ADHD vary within and between
countries. In the UK, the National Institute for Clinical Excellence does not recommend stimulant medication treatment for children and adolescents with moderate levels of impairment. Instead, individual or group-based parent-training/education programs are the first-line recommended treatment. According to this guideline, teachers should receive training about ADHD and its management, and provide behavioural interventions in the classroom to help children and adolescents with ADHD. Drug treatment is advised as the first-line treatment in the case of severe impairment only. In the USA however, stimulant medication treatment is highly recommended by the American Academy of Paediatrics along with other behavioural interventions. It is also advised in the USA that if one stimulant does not work at the highest possible dose, then clinician should recommend two stimulant medications or even a third formulation if two stimulants fail to achieve the expected outcomes. The USA guidelines stated that this recommendation is possible due to the safety and efficacy of stimulants in ADHD treatment and justified by occasional the idiosyncratic response to medication.

In Australia, the Royal Australasian College of Physicians has set out a detailed guideline on the treatment and management of ADHD and has made the following recommendations:

- Individuals with ADHD and their families and carers should be provided with information and education about ADHD and its impact, and the advantages and disadvantages of potential treatment strategies.
- Multimodal therapy is recommended for the treatment of ADHD in all age groups. This could include psychosocial management strategies, medication and educational interventions.
- An individualised management plan should be drawn up in collaboration with the person with ADHD and their parents/carers and teachers, taking into account:
  - The specific needs and expressed preferences of the person, and the circumstances of his or her family and culture.
  - The associated psychosocial problems, educational difficulties and comorbid conditions.
  - The suitability of the plan for the individual and their family, considering affordability, accessibility and acceptability.
- Not all people with ADHD will require pharmacological management.
• Medications should only be used when symptoms are pervasive across settings (e.g. school and home) and causing significant impairment in academic, social or behavioural function, and after careful consideration of non-pharmacological approaches. Clearly defined goals should be identified prior to commencing a trial of medication treatment.

• Medication should not be used as first-line treatment for ADHD in preschool-aged children.

• Patients receiving treatment for ADHD should be reviewed regularly (at least 6-monthly) to ensure that the management strategies remain appropriate and effective.

It is obvious that the treatment and management of ADHD varies from one country to another. Caution should be applied when generalisations are made about outcomes for children and adolescents with ADHD from diverse cultural backgrounds. It is generally agreed that psychosocial and psychostimulant interventions are the two main evidence-based treatments for ADHD\textsuperscript{19,184-185}. Multimodal treatment combines psychosocial management strategies and pharmacological treatment. While extensive research has been conducted on the short-term efficacy of pharmacological treatment, there is a relative paucity of research examining psychosocial intervention\textsuperscript{19}.

2.13.1. Psychosocial treatment

Psychosocial treatment covers a range of strategies, including education and training\textsuperscript{100}. The majority of psychosocial treatments include behaviour modification based on the theories and principles of classical conditioning, operant conditioning, cognitive behaviour techniques and social learning\textsuperscript{186}. Behaviour modification therapy\textsuperscript{185} aims to bring about changes in behaviour through modifying unwanted thoughts or beliefs in order to achieve better outcomes at home and at school. This therapy includes problem solving techniques, coping strategies, social skills, goal-directed technique and cognitive restructuring. It encourages learning socially appropriate behaviour using positive reinforcement, rewards and discipline. A meta-analysis by Fabiano et al\textsuperscript{186} suggested that behaviour modification is an effective intervention for children with ADHD that reduces the externalisation of symptoms and improves any other disruptive behaviour problems the person may have. The review also reported that behavioural
modification was effective for ADHD children with and without psychostimulant treatment.

Parent training programs have been developed to assist parents in the development of necessary skills to cope with their child’s ADHD behaviour, to anticipate difficulties, and to implement treatment plans\textsuperscript{187}. These programs aid parents in identifying problem behaviour, analysing the cause and developing strategies for managing and modifying the child’s ADHD behaviour. Family therapy is another technique that aims to improve family relationships through focusing on conflict resolution, effective communication, anger management and by developing ground rules and routines\textsuperscript{100}.

\subsection*{2.13.2. Pharmacological treatment}

Psychostimulant medications are the most common form of pharmacological intervention and the most widely prescribed treatment for ADHD. About two-thirds of the children diagnosed with ADHD receive psychostimulant medication\textsuperscript{21}. The psychostimulant medications dexamphetamine, methylphenidate and mixed amphetamine salts work in the brain to increase the availability of synaptic dopamine, which helps reduce hyperactivity, impulsivity and inattentiveness\textsuperscript{29}. In Australia, the stimulant medications dexamphetamine and methylphenidate are used for the treatment of ADHD\textsuperscript{100}. These are used in three different forms: short-acting stimulants or immediate-release formulations (4 to 6 hours); intermediate-acting stimulants or sustained-release formulations (6 to 8 hours); and long-acting stimulants or extended-release formulations (10 to 14 hours)\textsuperscript{188}. While both short-acting dexamphetamine and long-acting methylphenidate are considered cost-effective interventions for ADHD, dexamphetamine is less expensive, yet after subsidisation of the cost by the Pharmaceutical Benefits Scheme in Australia, methylphenidate is more cost-effective\textsuperscript{189}. Stimulant medication has been found to be effective in reducing the core symptoms of ADHD\textsuperscript{29}. However, the effectiveness of these medications is not maintained if the medication is discontinued\textsuperscript{190}. The American Academy of Child and Adolescent Psychiatry suggests that ongoing medication treatments that are taken for the management of other chronic disease or psychiatric illness should be applicable to ADHD treatment\textsuperscript{191}. 
Several concerns have been raised related to stimulant treatment due to inadequate research studying the health risks and benefits of the widespread use of medication treatment in children and adolescents. The concerns in particular are with the associated risk of long-term dependence, drug abuse and the safety of the medications in terms of side effects in children and adolescents\textsuperscript{33-36}, including possible cardiovascular complications\textsuperscript{37-39}. The USA Food and Drug Administration has issued three Public Health Advisories and a series of communications to health professionals and the general public regarding serious cardiovascular and psychiatric risks of ADHD medications\textsuperscript{192}.

2.13.3. Multimodal treatment

Combined interventions have been endorsed in almost all best practice guidelines for ADHD, yet the effectiveness of combined therapy with both medication treatment and behaviour management is uncertain\textsuperscript{193}. Some empirical studies comparing the efficacy of psychostimulant treatment with multimodal treatments indicate that the combination of stimulant medication with behaviour therapy had better outcomes over time in reducing ADHD symptoms\textsuperscript{185,194}. However, Sibley and colleagues\textsuperscript{195} found no differences in the therapeutic effects on symptoms when stimulant treatment was combined with behaviour therapy. Their results suggest that behaviour therapy may produce greater overall benefits on measures of impairment. Similar results were observed by Moreno-Garcíaa et al.\textsuperscript{196} who concluded that stimulant treatment, behavioural therapy and neuro-feedback administered individually produced similar therapeutic effects on the symptoms of children with ADHD.

Most studies demonstrating treatment efficacy have been short-term over several days or weeks. The Multimodal Treatment Study of Children with ADHD (MTA)\textsuperscript{197} conducted a randomised clinical trial to examine the effectiveness of medication and behavioural treatments over 14 months to address three questions: ‘How do long-term medication and behavioural treatments compare with one another?’; ‘Are there additional benefits when they are used together?’; and ‘What is the effectiveness of systematic, carefully delivered treatments vs routine community care’? The study compared four treatment groups: medication management, behavioural treatment, combination of medication and behaviour treatment, and community care, among 579 ADHD children aged 7–9.9 years. The effects of medication were found equivalent to
combined treatment over a 14-month period. Both medication and combined treatment were more effective than the behavioural management or community care alone. The dose of medication used in the combined treatment group was reported to be lower than the dose used in the group with medication alone to achieve the same outcome. The medication, however, did not improve other areas of the children’s functioning, such as oppositional behaviour, anxiety/depression, social skills, peer and parent-child relations and academic achievement. Moreover, despite the initial improvements, the differences between the treatment groups were no longer apparent at 2 and 3 years of follow-up. The MTA study was extended to 6 and 8 years of follow up after treatment, and once again no difference was observed between the treatment groups.

The core ADHD symptoms improved at 8 years when compared to the pre-treatment state; however, the participants continuing to take medication did not show a significantly greater improvement in other areas than the non-medicated participants. As such a short-term ADHD treatment showing improvement in childhood does not have lasting effects into the adolescent years.

2.14. USE OF STIMULANT TREATMENT

Stimulant medication is now prescribed as a first-line, often the only, course of treatment for ADHD, and the use of it has risen sharply in many parts of the world, particularly in Western and European countries. In the US, the prevalence of children receiving stimulant medication for ADHD was 6.1% in 2011 with approximately a 7% annual increase and a total 28% increase between 2007 and 2011. Healthcare Cost and Utilisation Project data have indicated that ADHD treatment rates quadrupled in the US between 1989 and 2000 with peaks in the rates at ages 7-12 years, and including children diagnosed as young as two years of age. In the UK, prescriptions of stimulants increased nineteen-fold from 6,000 in 1994 to 92,000 in 1997, and to 114,000 in 1999. The Netherlands, Norway and Sweden have reportedly seen significant increases in stimulant use. Similar growth was observed in Finland and Iceland.

2.15. STIMULANT MEDICATION USE IN AUSTRALIA

In Australia, the rise in the use of psychostimulant medication has mirrored that observed in the USA with a prevalence of 1.24% in 2010. Children as young as two years of age have been prescribed stimulants, causing community concern and
professional debate. From 1984 to 2000, the prescribing rate of psychostimulants increased by 26% per year, with an 8.46-fold increase from 1994 to 2000, ranking Australia third in psychostimulant use after the USA and Canada. Over the decade between 2000 and 2011 the prescribing rate of stimulant medications for ADHD increased by 72%. The dispensing rate of each drug (defined daily dose/per 1,000 population per day, a measure established by the World Health Organization) increased by 87% from 2.93 to 5.47 DDD/1,000 population per day in the past decade with dexamphetamine remaining the most commonly dispensed stimulant.

2.16. STIMULANT MEDICATION USE IN WESTERN AUSTRALIA

The DoHWA began collecting detailed data identifying the number of patients by age, gender, health district, prescriber and dosage for all ADHD stimulants not until August 2003 after the introduction of the WA Stimulants Regulatory Scheme which required notification of stimulant treatment submitted to the DoHWA by authorised prescribers. In October 2012, despite lack of detailed data, the DoHWA produced a retrospective analysis of the number of patients’ dispensed ADHD psychostimulants from 1998 to 2011 likely resulted in an underestimation and inaccuracy of the number of patients prescribed psychostimulants in WA prior to 2003. According to the report, the total number of WA prescribed psychostimulants for all purposes grew by over twenty-one-fold (from 880 to 18,715) from 1989 to 2002. Of the 18,715 estimated to be on stimulants in 2002, an estimated 17,237 (92.1%) were diagnosed with ADHD.

In 2002, 24% of the Australian children who received dexamphetamine prescription, which was the only Pharmaceutical Benefits Scheme subsidised ADHD drugs at that time, were living in WA, despite WA having about 10% of the total population. Collectively, the per capita prescribing rate for children peaked in 2002 by 142% above the national average. However, the per capita prescribing rate then fell by 50% with the major decline occurring between 2003 and 2007, while the prescribing rates grew in other states in Australia, and by 2011, it fell again with 11% below the national average. In 2012, 16,232 adults and children were notified as being treated with stimulant medication, an increase of 7.5% from 2011 (n=15,096). The inconsistent prescribing rates caused a significant academic, public and media debate. The intertemporal trends in WA stimulant prescribing rate has been attributed to either public awareness of ADHD behaviour as a medical disorder, a growing acceptance of
stimulant as an acceptable method of treatment for ADHD\textsuperscript{24}, or ‘regulatory capture’ which might have affected significant policy development and regulatory process in relation to ADHD to advance the interest of pharmaceutical industry instead of public interest\textsuperscript{216}.

2.17. CONTROVERSY OVER THE STIMULANT TREATMENT FOR ADHD

The use of stimulant medication to treat ADHD often lies at the core of the controversy surrounding the concept of ADHD. The constant rise in use of stimulant medication has been viewed as a means of social control through medicalising behaviour\textsuperscript{15-16,187,207,218}. Baldwin has argued that because there is no definitive scientific test for ADHD diagnosis, stimulant treatment should not be considered an acceptable treatment\textsuperscript{207}. According to him, “most psychiatrists and paediatricians apparently are more concerned with gaining social control over problem behaviour than with theorizing about psychopharmacology”\textsuperscript{219} (p. 455). He postulates that stimulant use not only benefits clinicians’ caseloads, but labelling child behaviour as a disorder serves also the financial interests of educational institutions. He said: “economic benefits clearly accrue to professionals who decide to ‘diagnose and prescribe’: teachers, psychologists and school principals all benefit financially when ‘special needs’ funding is reallocated around children who are educationally redefined as ‘ADHD’ or ‘ADD’”\textsuperscript{219} (p. 456).

Some parents may choose to adopt a medical model of ADHD diagnosis and stimulant treatment in an effort to prove that their child’s ADHD behaviour is not their fault\textsuperscript{220}. Purdie et al.\textsuperscript{187} argued that the improved behaviour arising from the use of stimulant medications has more benefits for teachers and parents than for the child, as the child’s benefit is limited to improved social functioning and not much improvement in emotional well-being or academic achievement. A child and adolescent psychiatrist, Dr Sami Timimi\textsuperscript{14}, has argued that medicalising behaviour and providing stimulant treatment disengages parents, teachers and doctors from their social responsibility to raise well-behaved children by offering a ‘pill for life’s problems’. He expressed concern that children taking long term medication for fixing their behaviours could potentially experience feelings of disability, deficit and powerlessness as a result.

Further, it has been argued that medicalisation of children’s behaviour is an objective of the pharmaceutical industry that creates and propagates the notion of ADHD in order to
increase the incidence of diagnosis, thus increasing their medication sales\textsuperscript{14,221}. Some commentators have even accused the pharmaceutical industry of “disease mongering”\textsuperscript{222} through intense consumer marketing, framing psychosocial states as medical conditions\textsuperscript{223}, offering financial incentives to parents and consumer support groups\textsuperscript{224}, and manipulating the educator’s role to facilitate the identification of children who do not conform to social norms\textsuperscript{225}.

The controversy and ongoing debate surrounding stimulant treatment for ADHD increases the importance of awareness that medication is not a panacea, nor a one-size-fits-all remedy. It provides a further basis for the notion that socio-cultural factors and cultural beliefs should be considered when treating children and adolescents with medication.

2.18. DISPARITIES IN THE USE OF STIMULANT TREATMENT

As well as the increase in the use of stimulant treatment for ADHD, the literature reports also that a large variation in use has occurred. Delays in seeking treatment for mental health disorders are generally greater in developing countries\textsuperscript{226}. The majority of research examining the variation in ADHD treatment within a nation has been conducted in the USA. In a survey in the USA, Fulton et al.\textsuperscript{41} reported that national variations occurred in stimulant medication treatment due to the type, number and ages of physicians within an area. The association between type and number of physicians and prescribing stimulant patterns was documented in Australia where paediatricians treated more ADHD children than child and adolescent psychiatrists, but prescribed less multiple psychotropic medications and lower stimulant doses than the psychiatrists\textsuperscript{227}. Some physicians have reported not following the best practice guidelines for treatment and often prescribing psychotropic medications to children with socioeconomic disadvantage in order to improve their behaviour and academic performance at school, on the basis that drug treatment is a quicker and cheaper option than any other intervention\textsuperscript{42}. The prescription stimulant pattern in people with disadvantage is complex. The prescription of psychotropic medications by physicians as a quick fix solution was not only observed in USA, but also in Canada\textsuperscript{43} and Australia\textsuperscript{228}, where children and adolescents living with disadvantage were more likely to receive stimulant medications for ADHD\textsuperscript{212,229}. The authors in another study using a nationally representative sample of the USA population, on the other hand, concluded that the
most disadvantaged group compared to the affluent group were more likely to meet criteria for ADHD, yet less likely to receive regular medication treatment\textsuperscript{47}.

Gender is well-known to be associated with variations in rates of stimulant treatment. Boys are reportedly more likely to receive stimulant treatment than girls across many nations\textsuperscript{21,230} including Australia\textsuperscript{73}. Gender differences in stimulant treatment are due to the fact that boys predominantly exhibit more externalising behaviours than girls who are more likely to manifest inattentiveness\textsuperscript{231}. Boys with higher levels of hyperactivity are seen as disruptive and a source of stress in a classroom situation, leading teachers to refer more boys than girls for ADHD diagnosis\textsuperscript{48}. Geographic variation was observed in the USA, where stimulant use was higher in the South and Midwest parts than in the Western part\textsuperscript{41}. In Australia, regional variations were reported with stimulant prescribing rates in urban areas 2.3 to 5.3 times greater than in remote areas\textsuperscript{45}. Children without health insurance have a lower rate of stimulant treatment, causing further differences in stimulant treatment\textsuperscript{232}.

\section*{2.19. CULTURAL VARIATIONS IN STIMULANT TREATMENT USE}

Substantial racial and ethnic disparities continue to exist for the use of stimulant treatment and ADHD health care services in children and adolescents. The majority of the research examining racial and ethnic disparities in psychotropic drug use for behavioural disorders and depression took place among African-American, Hispanic and Caucasian children in the USA. In general, ADHD in African-American children was underdiagnosed and undertreated\textsuperscript{233}. Findings from a telephone survey suggested that African-Americans and Hispanics were less likely than Caucasian people to find psychotropic medication acceptable, and more likely to accept counselling\textsuperscript{56}. A recent study examining trends in ADHD by ethnicity in the USA indicated an increased rate of medication treatment for ADHD in African-Americans from 2.6\%-4.1\% and Hispanics from 1.7\%-2.5\% in children aged 5–11 years in 2001–2010\textsuperscript{234}. The results showed, however, that the rate was still low among these ethnic minorities compared with their White counterparts, while the rate remained unchanged among Asian-Pacific Islander children. Based on a representative sample of the USA population in 2000–2002, the Caucasian children were two-fold more likely to receive medication treatment for ADHD (5.8\%) than African-American (2.8\%) or Hispanic (2.4\%) children\textsuperscript{53}. The findings were consistent with another study where Caucasian children were more likely
to get treated with medication for an ADHD diagnosis than African-American, Hispanics and other ethnic minority children raised in a non-English-speaking household\(^\text{232}\).

**2.20. CULTURAL EXPLANATORY MODEL**

Culture is defined as the values, beliefs, rituals, attitudes and behaviours that are passed down through generations within a social group\(^\text{63}\). Kleinman\(^\text{61}\) viewed culture as a means to derive symbolic meanings that have a significant influence on the individual’s experience of social reality. He compared medical systems to cultural systems and said that health, illness and health care were parts of a cultural system and must be understood in relation to each other. According to him, it is culture that shapes individual beliefs and perceptions of health and illness, and thus influences an individual’s diagnosis and health care decisions\(^\text{61}\) in particular for ADHD behaviour and its treatment. The definitions of social behaviour are not static, hence, labelling behaviours as ‘hyperactive’, ‘compulsive’, ‘normal’ and ‘abnormal’ are fluid entities that overlap, and thus need to be understood within a cultural context\(^\text{62}\). Cultural background influences the way an individual lives, including his or her perception, emotion, language, diet, dress, body image, family structures and attitudes toward problem behaviours and disorders. However, culture must be viewed also in its particular context in terms of historical, economic, political, and geographic elements\(^\text{61-62}\). While treatment choice for ADHD occurs within a cultural context, factors such as social, political, historical and socioeconomic status are likely to impact on immigrants and ethnic minorities in a host society and shape their behaviour accordingly\(^\text{235}\).

**2.21. ADHD HELP-SEEKING BEHAVIOUR MODEL FOR DIVERSE CULTURES**

In recognition that culture influences health problem recognition and treatment choice, the Behavioural Model of Health Service Use was developed by Andersen\(^\text{64}\) in 1995 to understand an individuals’ help seeking behaviours and access to health services. The aim of the model was to address factors affecting the utilisation of health services, to maximise the utility of resources, to improve the effectiveness of interventions, to reduce the service gap and to predict service utilisation. The model has been reformulated and expanded to explain mental health care decision making processes for ethnically diverse groups\(^\text{236}\). Eiraldi and colleagues\(^\text{65}\) further revised and proposed a
model of help-seeking behaviour for service utilisation among ethnic minority children and adolescents with ADHD. Theories underlying this model proposed that an individual’s understanding of ADHD influences his or her health behaviour, and by extension, that parental beliefs about ADHD affect the treatment choice for their children. The model proposed four stages of the help-seeking process and identified factors that may influence each stage: (i) problem recognition, (ii) decision to seek help, (iii) service selection and (iv) service utilisation (Figure 2). According to this model, the individual’s cultural factors influence their decision to adhere to treatment at any point in the help-seeking process.

An individual’s perception regarding the aetiology of behaviour is particularly important to consider, as they interpret behaviour based on their own sociocultural belief and experiences. Once the individual has recognised a problem, their perceived cause of it is likely to influence how they respond and where and what type of help they seek for that problem. The differing individual beliefs and understandings about the aetiology of ADHD mentioned earlier may explain the variations for stimulant medication use among ethnic minorities. Individuals who do not perceive hyperactive behaviour as a medical condition are less likely to seek stimulant treatment, and more likely to seek services that fit with their casual explanation of the problem.

Research has shown that African and South Asian Muslim immigrants, who believed their mental health problems were due to spirit possession and bad karma, were likely to seek guidance from their religious leaders. Similarly, Latino, African-American and Asian/Pacific Islander parents were more likely than Caucasian parents to endorse sociological and spiritual aetiologies for their child’s mental health problem, which resulted in lower mental health service utilisation among those children and youths.
Figure 2. Four stages of ADHD help seeking behaviour model. *Adopted from Eiraldi* [65]

The use of prescription medication was low in Hispanic and African-American children because the Latino and African parents did not perceive their child’s hyperactivity and learning disability as a problem for which they needed to seek treatment [57]. This is in accordance with the findings of DosReis et al. [58] who reported that African-American parents did not see ADHD behaviour as a pathology and had negative attitudes towards stimulant medication, such as ADHD medication, believing it would cause long lasting addiction that might be detrimental to the child’s career, cause negative social consequences and turn children into zombie-like creatures. Some African-American and Hispanic parents viewed their children’s ADHD behaviour as a problem, but did not recognise the problem as a medical condition; and therefore, did not find medication treatment acceptable for their children [238]. Instead, they found counselling and behavioural treatments more acceptable than medication treatment for ADHD [159]. On the other hand, Caucasian parents were more likely to accept a clinical explanation for their child’s ADHD behaviour and connected the child’s school performance to their ADHD problem, and hence found stimulant treatment more acceptable to treat ADHD [239].
Korean and US parent and teacher perceptions of ADHD and treatment were compared in a review where Korean parents and teachers attempted to take personal responsibility for the children’s ADHD behaviour, and tried disciplining the children to keep a “normal life” in harmony with others, as recommended by Korean traditional culture. The Korean parents were concerned that long term medication use was not good for their children, and the teachers felt that medications made the children look depressed. The Korean parents’ and teachers’ negative responses towards medication were influenced also by the fact that the medication did not increase children’s academic achievement, while the US parents and teachers positively responded towards medication, as it helped to reduce the symptoms of ADHD behaviour. Wilcox and colleagues conducted a study that was the first in India exploring the impact of parental understanding of ADHD on care-seeking behaviour. They found that Indian parents resisted a biomedical explanation to describe their child’s ADHD behaviour as being “sick”, and employed religious interventions to minimise the impact of ADHD. The parents, however, sought medical help when they perceived problems with their child’s academic performance.

### 2.22. CULTURAL STIGMA AND UTILISATION OF STIMULANT TREATMENT

A cultural understanding of ADHD intertwined with the perception of stigmatising experience towards ADHD may further influence the individual’s decision to seek stimulant treatment, especially among ethnic minorities. Compared with Caucasians, African-Americans different understanding of information about ADHD and are worried that medication treatment would lead to long lasting negative social consequences. African-American parents felt that their children might be subject to misdiagnosis and be over-medicated compared with Caucasian children, and feared that stimulant treatment would jeopardise their child’s future career and social relationships. Their beliefs about misdiagnosis and overmedication resulted in mistrust towards teachers when faced with their child’s problem behaviour. They were also concerned that ADHD treatment would raise question about their parenting skills and maintaining discipline.

To examine health disparities in ethnic minorities, Kendall and Hatton reported that differences in utilisation of ADHD related health services exist in one-fourth of the
cases due to the African-American child being less likely to be treated compared with the Caucasian child. The perceived stigma towards ADHD related health care service has been linked to the racial discrimination experiences of African-American children. The authors maintained that oppositional and aggressive behaviours, which are defined as ADHD symptoms, and allegedly found in juvenile offenders, are often prejudicially accredited to the characteristics of African-American adolescents and youth. There is a tendency to assume that violent behaviour is more prevalent in African-American and low socio-economic families than in Caucasian-American families. Therefore, Kendall and Hatton\textsuperscript{246} flagged concern that ADHD symptoms in African-American children were stereotypically more likely to be viewed as caused by poor parenting, lower intelligence, substance abuse, violence and poverty, than ADHD symptoms in Caucasian-American children.

2.23. USE OF STIMULANT MEDICATION FOR ADHD IN PEOPLE WITH DIVERSE CULTURAL AND LINGUISTIC BackgroundS IN AUSTRALIA

To the best of my knowledge there has not been a previous study examining cultural variations in stimulant use for ADHD treatment conducted in Australia. In one Australian study\textsuperscript{247} parents expressed a high level of stigma directed towards their child’s diagnosis with ADHD. The authors did not examine any possible cultural difference in perceived stigma, possibly because the participants in that study were predominantly Caucasians (98%). The Australian community is generally well-aware of ADHD\textsuperscript{217} and is generally positive towards stimulant treatment\textsuperscript{248}, yet believe that ADHD is over-diagnosed and over-treated in Australia\textsuperscript{249}. Once again, no cultural difference in attitude towards the acceptability of stimulant medication for ADHD has been examined.

Australia has become a culturally and linguistically diverse nation through migration over many years. According to the Australian Bureau of Statistics\textsuperscript{66} in 2013, there were 6.4 million people (28% of the Australian population) living in Australia who were born overseas. People born in the UK were the largest group of migrants with over 1.2 million, followed by those born in New Zealand (608,800), China (427,600) and India (369,700). WA had the highest proportion of overseas born residents at one-third of the population, and the largest increase in the proportion of overseas born people up from 30% in 2006. Immigrants and refugees in Australia reportedly have lower utilisation
rates of mental health services. Cultural differences in beliefs and attitudes towards mental health problems are the key factors in lower use of mental health services. Immigrants were more likely to seek help from friends and families than from professional sources. It is quite possible; therefore, that underutilisation of stimulant medication for ADHD treatment could be expected in ethnic minority groups in WA, as observed in the USA. Identifying factors responsible for cultural differences in stimulant prescribing patterns for ADHD treatment is important for shedding light on over-prescribing or under-prescribing of stimulant medication within certain cultural groups.

2.24. USE OF STIMULANT TREATMENT FOR ADHD IN ABORIGINALS

The Aboriginal and Torres Strait Islander population comprise three percent (669,900) of the total Australian population, and WA has the third largest (88,300) Aboriginal population. Research on ADHD in Aboriginals is scarce, and there is no published study on the prevalence of ADHD treatment in Australia, except that one study found evidence of ADHD in Aboriginal prisoners. The existence of core ADHD symptoms has been reported in Brazilian indigenous children and adolescents. A high prevalence of ADHD was found in Canadian Aboriginal children, but the authors suggested that unique learning and behavioural patterns among Aboriginal children may have erroneously led to an ADHD diagnosis. Another Canadian study examining stimulant prescription in Aboriginal children reported that a high level of psychotropic prescription for ADHD occurred due to the racial background of the child. As Aboriginal children with ADHD symptoms are more likely to be different from non-Aboriginal children with ADHD, studies of the use of stimulant medication in Aboriginal children with ADHD have been called for.

A handful of research studies has identified a high prevalence of mental health problems in Aboriginal adolescents and youths in Australia, yet the utilisation of mental health services is low. There is a paucity of research examining perceptions of mental health problems and wellbeing in Aboriginals. A systematic review of literature suggested that Aboriginal people understand mental health in terms of their culture and spirituality; family and community kinships; historical, social and economic factors; fear and education; and loss, which are very different from Western medical
constructions, and hence cannot be satisfactorily addressed via a medical model of treatment\textsuperscript{261-262}. Further, racial discrimination, colonisation, forced child removal\textsuperscript{263-265}, related stigma and mistrust towards the Western medical system\textsuperscript{265-266} are the factors associated with lower utilisation of mental health services in the Aboriginal population in Australia. Consequently, health professionals are advised that a holistic approach needs to be considered during psychiatric assessment of children and adolescents in the Aboriginal population and culturally appropriate service provided\textsuperscript{70,267-268}.

2.25. SUMMARY OF LITERATURE REVIEW

This review of the literature highlights that ADHD is a complex and contested concept. It is nearly impossible to give a satisfactory answer as to whether ADHD is a scientific fact or a factual opinion. The lack of ‘gold standard’ for the diagnosis of ADHD has led to considerable variation in the prevalence of ADHD within and between countries. Despite the polarisation of opinion regarding the aetiology and diagnosis of ADHD, the reported prevalence of ADHD has increased steeply. Psychostimulant medication for treatment of ADHD has further amplified the contention surrounding ADHD. While the effectiveness of stimulant treatment is still in question, the use of stimulant medication is on the rise. Yet there is a large variation in stimulant use across cultures. An individuals’ decision to use stimulant medication for ADHD treatment is based on his or her sociocultural notions of normal and abnormal behaviour. An individual is less likely to seek stimulant treatment if he or she does not identify ADHD as a medical condition. Parents’ interpretations of children’s behaviour may influence clinical decisions. Cultural understandings of ADHD behaviour may compounded by perceived discrimination and negative experiences among individuals from a minority cultural background in a host society and this may further lead to a variation in stimulant use.

Most of the literature reviewed originated from North America and Europe. There is a paucity of epidemiological studies on stimulant treatment use by ethnic minorities in Australia. As WA has a high rate of stimulant medication use, and a growing proportion of its population born overseas, it is important to study variations in the prescribing of stimulant medication within different ethnic segments of the populations and to decide if these variations are acceptable or appropriate objects for interventions. In the next chapter I will provide an outline of the overall thesis design including quantitative and qualitative research phases. Data storage and a consideration of the
ethical issues associated with research involving human participants will also be provided.
CHAPTER 3

OVERALL THESIS DESIGN

3.1 INTRODUCTION

To answer the research questions I have divided the thesis into two distinct parts – Part A and Part B pertaining to the quantitative and qualitative studies undertaken. Neither quantitative nor qualitative methods are sufficient by themselves to fully explore the detail of an area of research. As such, quantitative and qualitative methods complement each other and provide a holistic view of the research topic. This chapter describes a number of processes that were common to the both quantitative and qualitative studies, including ethics approval and data security.

3.2 THESIS STRUCTURE AND DESIGN

Part A, the quantitative research, is given prime emphasis in this thesis due to the extensive data collection from multiple sources, and linkage methods and complex analysis required to observe sociocultural variations in stimulant use in WA. This part involved the analysis of 27 years of data on nearly 700,000 individuals using the WA Birth Registrations, FCGS, Midwives Notification System (MNS), HMDC, Death Registrations and the linked MODDS. The goal of Part A was to investigate sociocultural differences in the use of stimulant medications for the treatment of ADHD. Two quantitative studies were carried out in Part A based on two separate cohort definitions.

Thesis Part B, the qualitative research, consisting of in-depth interviews with eight participants, complemented the quantitative studies in Part A. It elaborated on and sought to explain why individuals from Anglophonic background have a proclivity for stimulant use in the treatment of ADHD. The analysis of the qualitative data was used to assist in the understanding of the statistical results by exploring individuals’ perceptions of ADHD behaviours and their treatment in more depth.
Both the quantitative and qualitative data collection and analysis were conducted separately. However, the results from the quantitative work were used to inform the selection of participants and design of interview questions for the qualitative phase of the thesis. The findings of the two Parts were also connected in the discussion of the outcomes and interpretation of the overall study. The methodological framework of the thesis is presented in Figure 3.

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- Retrospective cohort
- Linked birth data to stimulant data (cohort one)
- Linked hospital data to stimulant data (cohort two)
- Logistic regression
- Cox proportional hazard ratio
- Multiple linear regression
- Multiple linear regression
- SPSS quantitative software
- Individual born in LPNO countries had lower stimulant use than those from HPNO countries
- Aboriginal had lower stimulant use than Australian born non-Aboriginal
- Why is there a higher stimulant use among HPNO?
- Selected eight participants with Caucasians background
- Questions to explore participants view towards ADHD and

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- Social constructivist approach
- Individual face-to-face in-depth interview
- Audio recording interviews
- Interview transcription into text
- Close reading text data
- Thematic analysis
- Participants description
- Descriptive analysis of the themes
- Explanation of quantitative results
- Interpretation of qualitative results
- Strengths, limitations and implications
- Recommendation for future studies

Figure 3. Methodological framework of the thesis
3.2.1 Part A - Quantitative study

Thesis part A comprised two quantitative cohort studies using the WADLS. Cohort 1 was used to investigate variations in stimulant medication use, according to parental country of birth and race, sex, geographic location and socioeconomic status. The cohort was selected from the WA Birth Registry as individuals who were born in WA between 1980 and 2007, and was linked to the MODDS to identify those who had stimulant prescription records for ADHD between 2003 and 2007. Parental country of birth was determined using the WAFCGS of the WADLS.

Cohort 2 was used to assist in validation of the findings from the first cohort, especially the results pertaining to the association between country of birth and disparities in the prescription stimulant use for ADHD treatment. In this study, individuals admitted into hospitals in WA in the first 25 years of their life between 1980 and 2007 were selected from the HMDC and, similar to the first cohort, were then linked to the MODDS from 2003-2007 to identify stimulant dispensing records for ADHD. Stages of the quantitative studies are presented in figure 4.

Figure 4. Stages of the quantitative phase
The details of data sources, data collection methods and statistical analysis using SPSS for the two cohorts are described in Chapter 4 Quantitative Methodology. The proposition that the results based on cohort 2 have value in at least a partial degree of validation of the results based on cohort 1 is because the two methods of cohort enrolment were affected by somewhat different limitations. Cohort 1 was limited to children born in WA and did not include children arriving with recent immigrants. Cohort 2 was limited to children, adolescents and young adults admitted to a WA hospital for any reason at least once. Whilst cohort 2 covered a large proportion of the state’s youth, it did not include those never hospitalised.

### 3.2.2 Part B - Qualitative study

The quantitative findings in Part A led me to explore reasons why stimulant use for ADHD in individuals from Anglophonic background is relatively high through a qualitative study in Part B. Thus the quantitative findings were used to guide participant recruitment and data collection methods. The stages of the qualitative study are indicated in figure 5.

![Figure 5. Stages of the qualitative study](image)
The sample for the qualitative study comprised eight participants who themselves or their child were diagnosed with ADHD. They were recruited through several avenues which are described in detail in Chapter 9 Qualitative Methodology. The participants were from Anglophonic background and resided in the Perth metropolitan areas in WA. Data were collected using standard interview techniques, and thematic analysis was carried out to interpret the information provided by the participants.

3.2.3 Study findings

The quantitative findings for cohort 1 and cohort 2 in thesis Part A are presented as manuscripts prepared for publication in Chapter 5, 6 and 7 of this thesis. The connections between the Part A quantitative studies and Part B qualitative study are described in Chapter 8. The qualitative results are presented as a manuscript for publication in Chapter 10. All manuscripts are listed in the declaration of thesis publication on page XVI. Both the quantitative and qualitative findings are integrated in the Discussion and Conclusion Chapter 11, which also includes strengths and limitations of the thesis, policy implications and recommendations for future research.

3.3 DATA STORAGE AND SECURITY

Data obtained from both the quantitative and qualitative studies were stored in electronic form on a desktop computer that was password protected. The network to which the computer belonged was protected by multiple firewalls to restrict outside, unauthorised access. Backup files were made of all electronic data and stored under equivalent conditions of security. Some outputs of statistical analysis in aggregated format, as well as interview transcripts were produced in hard copy, and stored in a ‘restricted-access’, locked cabinet, in a locked office to ensure security of the information. Storage facilities were kept locked at all times when not in use. Only my two supervisors and myself identified in the approved ethics application were permitted access to the data. Every syntax step for data coding and analysis was fully documented and filed so that it could be easily retrieved for sorting and cross referencing. The data will be securely maintained for a period of five years after publication of scientific manuscripts resulting from this work, after which time data will be destroyed in accordance with local policy.
3.4 ETHICAL CONSIDERATIONS AND APPROVAL

The professional researcher code of particular relevance to this study was the National Statement on Ethical Conduct in Human Research published by the National Health and Medical Research Council (NHMRC)\textsuperscript{269}. On this basis, the thesis proposal, including study design, methodology and analysis, underwent a peer review process and was then submitted to and approved by two institutional ethics committees: the Human Research Ethics Committee of The University of Western Australia (HREC-UWA); and the Human Research Ethics Committee, DoHWA. In addition, the ethics of an amendment to the research was approved by the HREC-UWA and a third ethics review group, the WA Aboriginal Health Ethics Committee (WAAHEC). The purpose of the amendment was to carry out a data analysis to investigate stimulant use for ADHD treatment in Aboriginal children, using the data approved by the DoHWA. In Australia, research focusing on collectives with special sensitivities, such as Aboriginals, requires a specific form ethics approval with high levels of participation by members or advocates of the relevant collective.

Throughout the course of the study, I made every effort to follow the ethical principles set down by the NHMRC guidelines for conducting this research and I believe that I attained the appropriate standards. The research questions and methods were designed to gain a better understanding of the complex concept and social process of ADHD, to contribute to knowledge, and to pursue and protect the truth. I was also strongly committed to maintaining confidentiality of data and I conducted my research in ways that respected and supported the cultural practices and values of Aboriginal communities.

De-identified, whole-population administrative data were used in both quantitative studies in Part A. In Australia, individual consent for analysis of de-identified administrative data was not required, provided that any conditions outlined by the relevant statutes were satisfied, as was the case for all aspects of the current research. The data were analysed in de-identified form and the results were aggregated for presentation. Moreover, the method of dissemination of results has no possibility of identifying individuals or causing harm of any kind to individuals whose data were included in the analyses.
However, due to the nature of the qualitative data collection, a different procedure was required to be undertaken in order to adequately respect individual autonomy and to ensure the privacy of research participants and confidentiality of information. In the qualitative study, I applied the following principles in accordance with the NHMRC guidelines:

- **Research integrity and justice:** My overarching aim was to act with integrity and to ensure that my practice as a researcher was unbiased and honest at all times. Each participant was given an information sheet, which provided them with sufficient detail about the research purpose, potential benefits of the study and data gathering methods. I was mindful of my responsibility to maintain confidentiality with respect to the participants’ identities and any potentially identifying elements of their stories. Confidentiality was particularly important in this qualitative study due to the small sample size. I informed them about their anonymity and their voluntary participation in this study. All participants were also assured that they could decline to answer any question or withdraw from the study at any time without reason or prejudice. I maintained a professional relationship with my research participants at all times during the study.

- **Beneficence:** I used pseudonyms for my informants during data recording and while processing interview notes, tapes and transcripts in order to preserve their confidentiality and create a respectful distance between the informants and myself as a researcher. I was mindful that some of the areas under discussion were sensitive and could cause emotional upset. To address this concern I designed the interview to be a pleasant and positive experience. The participants were assured that they could stop the interview should they have felt distress as a consequence of talking about their life struggles.

- **Respect:** Every participant in the study was given an informed consent form to sign and was provided with a copy of their signed consent for their records before the interview began. Each interview was recorded with the consent of the participant. They were informed that they could stop my recording at any time during the interview, even if they wish to continue to talk.
3.5 CHAPTER SUMMARY

This chapter has covered the overall thesis design. The thesis comprised two parts. Part A consisted of two quantitative retrospective cohort studies to investigate sociocultural differences in the use of stimulant medication for ADHD treatment, using whole-population de-identified linked data. Part B involved a qualitative study using in-depth interviews with participants from Anglophonic background to understand individuals’ sociocultural perceptions of ADHD behaviour and stimulant medication treatment in this group. The ethical procedures in both parts of the thesis were given detailed consideration.
CHAPTER 4

QUANTITATIVE METHODOLOGY

4.1 INTRODUCTION

To answer the thesis questions in Part A – sociocultural disparities in stimulant use, I carried out two main quantitative studies. The first study was a WA population-based retrospective cohort study that included all individuals born in WA from 1980 to 2007 for whom records of both country of birth and race were available in the WA linked data collections for both their mother and father, and then followed through to link to the MODDS between 2003 and 2007 to find any treatment record with stimulant medications for ADHD. The second study included all children, adolescents and young adults who were first admitted to hospital in the first 25 years of life from 1980 to 2007, and then similar to the first study followed through to ascertain stimulant medication records for ADHD by linking the MODDS between 2003 and 2007. This study also served as a validation of methods and findings of the first study. I utilized the best practiced WADLS to link the administrative data sets such as the WA Birth Registry, MNS, Death Registry, HMDC, and used the WAFCGS to ascertain anonymous parental links for the individuals in the quantitative phase. In this chapter I describe particular detailed information on the WADLS, WAFCGS, databases, data collection and data analysis procedures for the quantitative studies.

4.2 WA DATA LINKAGE SYSTEM (WADLS)

WA whole-population based data linkage system (WADLS) links data related to the same person from various different sources and was established in 1995 with a three year grant from the Lotteries Commission of WA. The WADLS is currently funded by the DoHWA and managed by Data Linkage Branch, DoHWA. The Data Linkage Branch routinely links administrative health data to other data collections for the entire WA population, and provides linked data for developing policy, planning, and epidemiological and health services research.
Nine core data sets are regularly linked through the WADLS, namely Birth Registrations, Marriage Registrations, Death Registrations, MNS, HMDC, Emergency Department Data Collection, Cancer Registry, Mental Health Information System and Electoral Roll (Figure 6). WA Birth Registrations back to 1974, Marriage Registrations from 1984, and WA Death Registrations since 1969 are obtained from the WA Department of the Attorney General at the beginning of each month and linked by the middle of that month. The MNS managed by the DoHWA, collects records of all attended births in WA since 1980 and comprises over 13.5 million records. The HMDC from 1970, Emergency Department Data Collection from 2002, Cancer Registry since 1982 and Mental Health Information System as early as 1966 are also administered by the DoHWA. The WA Electoral Roll from 1988 is obtained from the WA Electoral Commission is also regularly linked through the WADLS.

There are other data sets such as the Aged Care Assessment Program, MODDS, Reproductive Technology Register, Residential Care Line, and WA Notifiable and Infectious Disease that are administrated by the DoHWA and that have been linked to these core data sets. Apart from the WA Health data, a variety of other state databases are also part of the WADLS. These databases are Drug and Alcohol, Insurance Commission, Main Roads and Silver Chain Nursing Association. A number of research datasets have also been linked to the core datasets of the WADLS. The research datasets include Busselton Surveys, survey of Kimberley Aboriginal people, Crime Research and Road Injury.
Core Datasets
- Birth Registrations Since 1974
- WA Cancer Registry Since 1982
- Death Registrations Since 1969
- WA Electoral Roll Since 1988
- Emergency Department Data Collection Since 2002
- Hospital Morbidity Data System Since 1970
- Marriage Registrations Since 1984
- Mental Health Information System Since 1966
- Midwives Notifications Since 1980

WA Health
- Aged Care Assessment Program
- Monitoring of Drugs of Dependence
- Reproductive Technology Register
- Residential Care Line
- WA Notifiable & Infectious Disease

Family Connections Genealogical System
- Parent-child links through birth, death and marriage registrations

Research Databases
- Busselton Surveys
- Crime Research
- Fremantle Diabetes
- Kimberley Survey
- MONICA IHD
- NHF Surveys
- Road Injury

Other State Data Systems
- Drug & Alcohol
- Insurance Commission WA
- Main Roads WA
- Silver Chain Nursing Association

Geocoding
Over 6 million records
Over 1 million individuals

Figure 6. WA Data linkage system
4.3 WA FAMILY CONNECTIONS GENEALOGICAL SYSTEM (WAFCGS)

WA is a state occupying the western third of the Australian continent with an estimated population of 2.5 million, around 11% of the national total in 2013\(^{271}\). WA is a highly urbanised state with over three quarters (78%) of its population living in the greater metropolitan city. The WAFCGS was established in 2003 as an adjunct to the WADLS in order to create and store family links between genealogically related individuals in WA, and to be used as a resource in conjunction with health data for family-based epidemiological and genetic health risk assessments\(^{272}\). Using probabilistic matching techniques, the WADLS connects records from multiple sources for the same individual, family and event\(^{72}\). Only a few researchers to date have used the genealogical database, focusing on cancer and genetic risk assessment\(^{273-274}\). It appears that this doctoral research project is the first genealogical study to use the WAFCGS to pursue an objective in social epidemiology more so than genetics per se by using parental country of birth as a marker of cultural heterogeneity.

By the time of the research, the WAFCGS had created genealogical links for 1.7 million births in WA since 1974\(^{275}\). It was designed to provide maximum protection for individual privacy by completely separating personal identifiers from actual health data, and replacing them by unique identifiers that link the genealogical relationship\(^{276}\). No actual clinical data were stored in the genealogical indices and the identifiers were encrypted when provided to approved health research projects in order to make the identifiers meaningless outside of the specific research context\(^{272}\).

Using the WAFCGS parent-child relationships were identified through birth registration, and supplemented with midwives notifications and death registration information (See Figure 7 for illustration). Thus parental country of birth information was extracted and linked to the MODDS data for individuals in order to study the parental country of birth and race influences on an individual’s stimulant medication use for ADHD.

4.4 PROCESS OF LINKAGE

The linking system that creates and stores family links between genealogically related individuals in WA is structured using a *chain of links*\(^{272}\) where each link is associated with a record in one of the data sets in the WADLS, and a single record may be in more
than one chain. For example, in Figure 8, two HMDC records H1 and H3 for Paul with the same linked chain number 01 are stored in the master links file. Another record M3 from the MODDS links to Paul and is also stored with the same chain number 01.

A single HMDC record H2 links to Sue is added with chain number 02. As the birth registrations are added, Sue is linked to her HMDC record. This link is added to the master links with B2 for birth record 2 and chain number 02, the same chain as H2. The same birth record can also be linked to the HMDC record H4 for the baby Mark. Birth record B2 also links to Mark’s hospital record H2, and as neither is in the master links, they are added with a new chain number of 03. A MODDS record M1 that links to Mark is stored with the same chain 03 in the master links. Genealogical links between Sue and Mark could be identified using parent-child information from Birth Registrations, and stimulant medication information was found from the MODDS. While information on stimulant medication for Paul was identified, no genealogical link was found. It was possibly because Paul was not born in WA, thus parental information could not be ascertained.

It may warrant emphasis that the names described are for illustration purposes only. The master links file contains no intelligible information from other databases, and neither can it alter any databases. For example, names such as Sue and Mark simply do not exist in the master links file.
Figure 7. Genealogical links between parents and child with stimulant records.

Adapted from D’Arcy Holman: *Introductory analysis of linked health data* [277].
4.5 QUANTITATIVE STUDY ONE

The first study of the thesis involved a longitudinal study selecting a cohort of individuals recorded in the WA Birth Registrations between 1 January 1980 and 31 December 2007 and was linked to the MODDS from 1 January 2003 to 31 December 2007, maintained by the DoHWA to permit outcome evaluations of treatment with stimulant medications for ADHD. Parent-child relationships as well as parental country of birth and race were ascertained from the WA Birth Registrations and MNS, but were available only for parents who had at least one record in one of these databases.

4.5.1 Data source for quantitative study one

Data was collected from multiple linked WA administrative databases for the quantitative phase (see table 2 for data sources).
Table 2. Summary of data sources for quantitative phase

<table>
<thead>
<tr>
<th>Data Sources</th>
<th>Period</th>
<th>Single Records</th>
<th>Data fields</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cohort data-Birth</td>
<td>1980-2007</td>
<td>700,466</td>
<td>De-identified person ID</td>
</tr>
<tr>
<td>Cohort data-Hospital</td>
<td>1980-2007</td>
<td>727,534</td>
<td>De-identified person ID</td>
</tr>
<tr>
<td>Cohort data-parents</td>
<td>1980-2007</td>
<td>699,704</td>
<td>De-identified person ID, De-identified parents ID, relationship to the person</td>
</tr>
<tr>
<td>WA Birth Registrations</td>
<td>1 Jan 1980 - 31 Dec 2007</td>
<td>692,917</td>
<td>De-identified mother ID, unique record ID, date, month and year of birth, registration year, place of birth, birth weight, flag to indicate multiple birth, flag to indicate live birth, birth weight, sex, age of previous child, mother's age, mother's place of birth, mother's occupation, mother's Indigenous status, father's age, father's place of birth, father's Indigenous status and parents' place of marriage</td>
</tr>
<tr>
<td>WA Midwives Notifications System</td>
<td>1 Jan 1980 - 31 Dec 2007</td>
<td>699335</td>
<td>De-identified person ID, unique record ID, age in years at time of delivery, state and postcode of residence, ethnicity, Indigenous status, place of birth, total number of previous pregnancies, flag to indicate smoking during pregnancy, child's date of birth, child's sex, weight, flag to indicate live birth, flag to indicate multiple birth, 1996, 2001 and 2006 SEIFA and ARIA scores</td>
</tr>
<tr>
<td>Monitoring of Drugs of Dependence System</td>
<td>1 Jan 2003 - 31 Dec 2007</td>
<td>15,700</td>
<td>De-identified person ID, unique record ID, date, month and year of birth, postcode of residence, flag to indicate if notification, notification date, notification reason, flag to indicate if re-notification, re-notification date, re-notification reason, flag to indicate if termination, termination date, termination reason, flag to indicate if patient is being treated within the prescribing code, date prescribed, drug name, drug strength and quantity of drug prescribed</td>
</tr>
<tr>
<td>Stimulant Notification</td>
<td>1 Jan 2003 - 31 Dec 2007</td>
<td>15,700</td>
<td>De-identified person ID, unique record ID, date, month and year of birth, flag to indicate if notification, notification date, flag to indicate if re-notification, re-notification reason, flag to indicate if termination, termination date, termination reason, date dispensed, date prescribed, drug name, drug form, drug strength and quantity of drug dispensed</td>
</tr>
<tr>
<td>Stimulant Dispensing</td>
<td>1 Jan 2003 - 31 Dec 2007</td>
<td>15,700</td>
<td>De-identified person ID, unique record ID, date, month and year of birth, flag to indicate if notification, notification date, flag to indicate if re-notification, re-notification reason, flag to indicate if termination, termination date, termination reason, date dispensed, date prescribed, drug name, drug form, drug strength and quantity of drug dispensed</td>
</tr>
<tr>
<td>WA Death Registrations</td>
<td>1 Jan 1980 - 31 Dec 2007</td>
<td>11,871</td>
<td>De-identified person ID, unique record ID, postcode of residence, place of death, sex, age at death, cause of death, place of birth</td>
</tr>
</tbody>
</table>
4.5.1.1 Western Australian Birth Registrations

The cohort for this study comprised children and adolescents who were born in WA between 1980 and 2007 and who thus most had parental links available. The cohort data and parental links were generated by the Data Linkage Branch from the genealogical database. There were 700,466 records for the birth cohort, and 699,704 sets of parental links for mothers and fathers were individually extracted for this study.

The WA Birth Registrations comprised one of the core datasets obtained from the WA Office of the Registrar General and routinely linked by the WADLS to other administrative health data sets. This database was the prime one used by the WAFCGS to define relationships between parents and children. Since 1974, the Birth Registrations had recorded births for all children born and subsequently registered in WA and captured detailed information about the child and its parents. For the purpose of this research, the extracted birth records covered the years from 1980 to 2007 and numbered 692,917. The data fields selected were de-identified and encrypted person identifier, encrypted unique record identifier, day, month and year of birth, registration year, place of birth, birth weight, a flag to indicate a multiple birth, a flag to indicate a live birth, birth weight, sex, age of previous child, both mother’s and father’s information on age, occupation, Indigenous status, place of birth and place of marriage.

4.5.1.2 WA Midwives Notifications System (MNS)

The MNS was established under the authority of the Health Regulations 1994, and was an administrative data collection which compiled information on all births attended by a midwife in WA since 1980. The MNS was managed by the DoHWA, and comprised over 13.5 million records of public and private hospitals, and home births including women whose usual place of residence is outside WA, who nevertheless gave birth in WA. The midwife records included any livebirth or stillbirth of at least 20 weeks gestation or, if the gestation period is unknown, with a birth weight of at least 400 grams. Information on women resident in WA who gave birth outside WA was excluded278.

The information captured in the midwife records embraced pregnancy care, services and outcomes, which included personal and demographic, medical and obstetric information about the mother. The midwives also collected information on the labour, delivery and
condition of the infant for the period from time of birth to time of discharge or transfer from the birth site, or death, whichever was soonest in order to help to identify the parent-child relationships.

The midwife records included in this research project were those from 1980 to 2007 and comprised 699,335 single records. The data fields selected were de-identified and encrypted mother ID, unique record ID, age in years at time of delivery, state and postcode of residence, ethnicity, Indigenous status, place of birth, total number of previous pregnancies, a flag to indicate smoking during pregnancy, child's date of birth, child's sex, weight, a flag to indicate a live birth, a flag to indicate a multiple birth, as well as socioeconomic status and geographic locations.

4.5.1.3 Death Registrations

The WA Death Registrations was administered under the Births, Deaths and Marriages Registrations Act 1998 (WA) by the WA Registrar of Birth, Deaths and Marriages of the WA Department of the Attorney General. The register recorded all deaths occurring in WA. Stillbirths, death in utero after from 20 weeks gestation or at greater than 400 grams birthweight were recorded in both the birth and deaths registers.

The death data extracted for the period from 1 January 1980 to 31 December 2007 contained 11,871 single records. The data fields included were de-identified, encrypted person ID, unique encrypted record ID, postcode of residence, place of death, sex, age at death, cause of death and place of birth.

4.5.1.4 Monitoring of Drugs of Dependence System (MODDS)

The MODDS contained all records for ‘schedule 8 medicines’ which were also referred to as drugs of addiction or drugs of dependence as defined and regulated by the Poisons Act 1964 (WA) and the Poisons Regulations 1965 (WA). These ‘schedule 8 medicines’ included opioids, stimulants (methylphenidate and dexamphetamine) and benzodiazepines (flunitrazepam and alprazolam) and all information about these three types of drugs of addiction were routinely collected by the MODDS. For the purpose of the research, both stimulants data sets, which comprised stimulant notifications and stimulant dispensing data, were used (Figure 9).
4.5.1.5 Stimulant Notification Data

Since the initiation of Stimulant Regulatory Scheme in WA in 2003, to prescribe stimulant medication, specialist medical practitioners in paediatrics, psychiatry, child and adolescent psychiatry, neurology, paediatric neurology, respiratory and sleep, thoracic and rehabilitation medicine must have been authorised and assigned Stimulant Prescriber Numbers by the DoHWA under the provisions of the Poisons Regulations 1965 (WA)\(^ {280} \). Under the Regulations, stimulant medications could only be prescribed for the treatment of ADHD, brain damage, depression or narcolepsy. For the purpose of this study, the stimulant data sets were used where stimulant was prescribed for ADHD treatment only.

The authorised stimulant prescribers were required to submit a *Notification of Treatment Using Stimulant Medication Form* (Appendix III) to the DoHWA when they commenced prescribing treatment (a ‘notification’), modified treatment (a ‘re-notification’) or ceased treatment (a ‘termination’) with dexamphetamine or methylphenidate. They were required to provide treatment information such as name and dose of stimulant, health condition for which the stimulant was required, date, any co-morbidities, and patient and prescriber details. They also needed to notify if a general medical practitioner was be to allowed to co-prescribe stimulant according to the authorised prescriber’s instructions. In addition to submitting a notification, the authorised stimulant prescriber needed to get a special authorisation before they commenced prescribing if the treatment fell outside the criteria set out in the Stimulant

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Figure 9. Monitoring of Drugs of Dependence System database

![Monitoring of Drugs of Dependence System database](attachment:image.png)
Prescribing Code\textsuperscript{280}. For example, if a patient had a history of substance abuse or psychosis, if the dose was above 60mg dexamphetamine or 120 mg methylphenidate per day, or the patient was less than four years of age, the specialist was obliged to obtain written authority from the DoHWA.

The stimulant notification data for this study covered the period from 1\textsuperscript{st} January 2003 to 31 December 2007 and contained 15,700 single records. The data fields extracted from the stimulant notification data were de-identified and encrypted person identifier, unique record identifier, date, month and year of birth, notification date, notification reason, re-notification, re-notification reason, termination, termination date, termination reason, stimulant name including its strength, and stimulant quantity (Table 1).

\subsection*{4.5.1.6 Stimulant Dispensing Data}

When the stimulant prescription was dispensed at a WA pharmacy, information related to the dispensing was recorded electronically at each pharmacy using commercially developed pharmacy dispensing software, and then forwarded to the DoHWA at the end of each month to be stored in the MODDS. Pharmacies were required by legislation to provide patients’ personal details, prescriber’s details, and stimulant details including name, strength and dose, as well as the date each time patients were dispensed their stimulant. As such, a patient could have multiple dispensing dates per prescribed date\textsuperscript{74}.

Similar to the stimulant notification data, the stimulant dispensing data covered the period from 1\textsuperscript{st} January 2003 to 31 December 2007 and contained 15,700 single records. The data fields extracted from the stimulant dispensing data were the same as those from the stimulant notification data above and included the date the prescription was dispensed.

\subsection*{4.5.2 Sample selection}

Individuals who had a WA birth registration between 1980 and 2007, and who had parental identities available from the WAFCGS were selected for this study with the total sample size being 692,761. This cohort was then linked to the stimulant records from 1 January 2003 – 31 December 2007 to determine those who had a stimulant record (n=13803) and those who did not (n=678958).
4.5.3 Variables and measurement

4.5.3.1 Outcome variable

The outcome, dispensing of prescription stimulant medication, was defined as having at least one record of prescription stimulant dispensed at any time between 1 January 2003 and 31 December 2007.

4.5.3.2 Exposure variables

Country of birth

Parental country of birth was classified according to the electronic Human Relations Area Files (eHRAF) World Cultures, an anthropological database that contained information on most aspects of cultural and social life, and classified cultures into eight major geographical regions: Asia, Europe, Africa, North America, the Middle East, Oceania (including Australia and New Zealand), Central America and the Caribbean, and South America\textsuperscript{281} (Table 3). Central America and the Caribbean and South America were combined into one category, and referred to as ‘South America’. Because the majority of parents were born in Australia, which according to the eHRAF fell under Oceania, this category was referred to as Australia and New Zealand.

A preliminary analysis was conducted to examine national groupings of sub-regions such as Central Africa, Northern Africa, Southern Africa, Western Africa, etc. classified by the eHRAF World Cultures database\textsuperscript{282}. The preliminary results (Figure 10) showed a tendency for reduced stimulant use for ADHD in individuals with parents born in Africa, Asia, the Middle East or South America, compared with individuals with parents born in Australia or New Zealand, Europe or North America. Based on this analysis the parental country of birth was then aggregated into LPNO and HPNO countries. Thereafter, the comparison between parental countries of birth was based on the LPNO and HPNO status of each parent.
Table 3. Country of birth grouped by region and sub-region

<table>
<thead>
<tr>
<th>Region</th>
<th>Sub-Region</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>Central Africa</td>
<td>Burundi, Chad, Congo, Eritrea, Rwanda, Sudan, Zaire</td>
</tr>
<tr>
<td></td>
<td>Eastern Africa</td>
<td>Djibouti, Ethiopia, Kenya, Seychelles, Somalia, Tanzania, Uganda</td>
</tr>
<tr>
<td></td>
<td>Northern Africa</td>
<td>Algeria, Egypt, Libya, Mali, Morocco</td>
</tr>
<tr>
<td></td>
<td>Southern Africa</td>
<td>Angola, Botswana, Comoros, Namibia, Madagascar, Malawi, Mauritius, Mozambique, Lesotho, South Africa, Swaziland, Zambia, Zimbabwe</td>
</tr>
<tr>
<td></td>
<td>Western Africa</td>
<td>Burkina, Cote d'Ivoire, Guinea, Nigeria, Ghana, Togo, Senegal, Gambia, Sierra Leone, Liberia</td>
</tr>
<tr>
<td>Asia</td>
<td>Central Asia</td>
<td>Afghanistan, Nepal, Bhutan</td>
</tr>
<tr>
<td></td>
<td>East Asia</td>
<td>China, Japan, Hong Kong, Korea, Mongolia</td>
</tr>
<tr>
<td></td>
<td>South Asia</td>
<td>Bangladesh, India, Myanmar, Pakistan, Sri Lanka, Maldives</td>
</tr>
<tr>
<td></td>
<td>South East Asia</td>
<td>Cambodia, Indonesia, Laos, Malaysia, Philippines, Singapore, Taiwan, Thailand, Vietnam</td>
</tr>
<tr>
<td>Europe</td>
<td>British Isles</td>
<td>UK, Scotland, Ireland, Netherlands</td>
</tr>
<tr>
<td></td>
<td>Scandinavia</td>
<td>Denmark, Iceland, Finland, Norway, Sweden</td>
</tr>
<tr>
<td></td>
<td>South Eastern Europe</td>
<td>Albania, Austria, Belarus, Bosnia, Bulgaria, Croatia, Cyprus, Czechoslovakia, Estonia, Georgia, Greece, Hungary, Kosovo, Latvia, Lithuania, Macedonia, Moldova, Montenegro, Poland, Romania, Russia, Tajikistan, Turkmenistan, Serbia, Slovenia, Ukraine, Uzbekistan and Yugoslavia</td>
</tr>
<tr>
<td>Central America and the Caribbean</td>
<td>Southern Europe</td>
<td>Belgium, Italy, France, Germany, Luxembourg, Malta, Monaco, Portugal, Spain, Switzerland</td>
</tr>
<tr>
<td></td>
<td>Caribbean</td>
<td>Bahamas, Barbados, Cuba, Dominican Republic, Dominica, Haiti, Jamaica, Puerto Rico, Trinidad and Tobago, West Indies</td>
</tr>
<tr>
<td></td>
<td>Central America</td>
<td>Belize, Costa Rica, El Salvador, Guatemala, Honduras, Nicaragua, Panama, Saint Vincent and the Grenadines</td>
</tr>
<tr>
<td></td>
<td>Caribbean</td>
<td>Mexico</td>
</tr>
<tr>
<td></td>
<td>Maya Area</td>
<td><em>Overlap with Central Mexico: Guatemala, Mexico</em></td>
</tr>
<tr>
<td>Middle East</td>
<td>North America</td>
<td>Regional and Ethnic Cultures (e.g. African American)</td>
</tr>
<tr>
<td></td>
<td>Eastern Woodlands</td>
<td>Canada, United States</td>
</tr>
<tr>
<td></td>
<td>Arctic and Subarctic</td>
<td><em>Overlap with Polynesia e.g. Hawaii</em></td>
</tr>
<tr>
<td></td>
<td>North West Coast and California</td>
<td></td>
</tr>
<tr>
<td></td>
<td>South West and Basin</td>
<td></td>
</tr>
<tr>
<td>Region</td>
<td>Countries</td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td>---------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Oceania</strong></td>
<td>Australia, Christmas Islands, Cocos Keeling islands, Torres Strait Islands, Papua New Guinea, Timor, Solomon Islands, Vanuatu</td>
<td></td>
</tr>
<tr>
<td><strong>Melanesia</strong></td>
<td>Australia, Christmas Islands, Cocos Keeling islands, Torres Strait Islands, Papua New Guinea, Timor, Solomon Islands, Vanuatu</td>
<td></td>
</tr>
<tr>
<td><strong>Micronesia</strong></td>
<td>Palau, Micronesia, Kiribati, Marshall Islands, Nauru,</td>
<td></td>
</tr>
<tr>
<td><strong>Polynesia</strong></td>
<td>French Polynesia, Hawaii, Fiji, New Caledonia, New Zealand, Samoa, Tonga</td>
<td></td>
</tr>
<tr>
<td><strong>South America</strong></td>
<td>Bolivia, Brazil, Colombia, Ecuador, Paraguay, Peru, French Guiana, Guyana, Surinam, Venezuela</td>
<td></td>
</tr>
<tr>
<td><strong>Amazon and Orinoco</strong></td>
<td><strong>Central Andes</strong>&lt;br&gt;These countries overlap with Amazon and Orinoco. Eastern South America, North West South America, and Southern South America</td>
<td></td>
</tr>
<tr>
<td><strong>Eastern South America</strong></td>
<td>As above</td>
<td></td>
</tr>
<tr>
<td><strong>North West South America</strong></td>
<td>As above</td>
<td></td>
</tr>
<tr>
<td><strong>Southern South America</strong></td>
<td>Argentina, Chile, Falkland Islands, Uruguay</td>
<td></td>
</tr>
</tbody>
</table>
Figure 10. Distribution of stimulant medication among parental country of birth by region and sub-region

Abbreviations: CAAC = Central America and the Caribbean, ME = Middle East, NA = North America, SA = South America, UK = Unknown
Residential remoteness and socioeconomic status

Indirect measures of residential remoteness and socioeconomic status were derived from the Australian Bureau of Statistics (ABS) five-yearly population census: Accessibility/Remoteness Index of Australia (ARIA)\textsuperscript{283}, and Socio-Economic Index for Areas (SEIFA) for Areas (SEIFA) for 1996\textsuperscript{284}, 2001\textsuperscript{285} and 2006\textsuperscript{286} were used. ARIA was Australia’s most authoritative geographic measure of remoteness and derived from measures of road distances to the nearest urban centre. These road distance measures were then used to generate a remoteness score for any location in Australia and were assigned to each level of statistical unit including collector’s district, statistical local area, local government area and postal area. The ABS constructed aggregate measures of socioeconomic status based on information from the Census. The Index of Relative Socioeconomic Disadvantage (IRSD), one of the four SEIFA indices, was used as a measure of socioeconomic status in this study. The IRSD score was composed from a wide range of indicators reflecting disadvantage, such as low income, low educational attainment, unskilled occupations, high unemployment, and other characteristics such as housing condition and Indigenous status.

In the WADLS, birth and midwives data were routinely geocoded. The ARIA and IRSD scores at the collector’s district level, which was the smallest statistical unit of 220 households in the metropolitan area, for example, were used in this study. Where available, the ARIA and IRSD values for 1996 were used for the period from 1 January 1980 to 31 December 1996, 2001 values were used for 1 January 1997 – 31 December 2001, and 2006 values were used after that period. ARIA scores were grouped into three levels: metropolitan (used as the reference category), rural and remote. The IRSD scores were categorised into five levels of socioeconomic disadvantage: most disadvantaged (the lowest <10\% of IRSD scores of the WA general population), more disadvantaged (10\% to <25\%), little disadvantaged (25\% to <50\%), less disadvantaged (50\% to <75\%), and least disadvantaged (\geq 75\%, used as the reference category). The five levels of categorisation for socioeconomic status using percentiles were an effective way to offer a focus on the most disadvantaged 10\% of the population and this approach has appeared often in research articles\textsuperscript{287}.\par
Sex

Information on individual’s sex was available and classified as female and male. Individuals who did not have any information on sex, were recorded as ‘transsexual’, ‘other’ or ‘unknown’ were categorised as unknown in the analysis.

Age

Individual’s date of birth was available in both the Birth Registrations and the MODDS databases. The date of birth was crossed checked in both data sets, and if the value of the date of birth variables differed in cohorts birth and MODDS data, then the value of date of birth for analysis was chosen from the birth registrations. Age at initial stimulant medication use between 2003 and 2007 was calculated by subtracting date of birth from dispensed stimulant medication date. Age in years was categorised into four age groups: 0-4 years (pre-primary school age), 5-12 (primary school age), 13-17 (high school age) and 18 and up (adulthood).

Indigenous status

Information on parental Indigenous status was available from birth registration. If any of the parents was recorded as either an Aboriginal person or Torres Strait Islander, they were considered to be ‘Aboriginal’ (the term preferred by Indigenous communities in WA). In this study, there were 22,024 individuals who had Aboriginal or Torres Strait Islander parents. Of these, 12,518 had both parents Aboriginal, 4,902 had only Aboriginal fathers and 4,604 had only Aboriginal mothers.

4.5.3.3 Exclusions

Exclusion criteria were stillborn (n=5,108), birth status unknown (n=41) or missing (n=89), died before 2003 (n=6,203) or parental records were unavailable (n=156) in the genealogical database.

4.6 QUANTITATIVE STUDY TWO

The second study was concerned with all children and adolescents who were first admitted to hospital in the first 25 years of life from 1980 to 2007. The aim of this study was to examine individuals’ country of birth and race influences on the stimulant medication use for ADHD treatment. Unlike the Study One where parental country of
birth and race were identified from the Birth Registrations, this cohort was selected using the HMDC. The HMDC data was selected in order to pick up individuals born overseas and their country of birth. Enrolling a cohort based on hospital admission may pose a question about the external validity of the cohort, and has been addressed as a limitation in the discussion chapter. Similar to Study One using the WADLS, this cohort was linked to the MODDS from 2003 to 2007 to permit outcome ascertainment – dispensed stimulant prescription for ADHD for children and adolescents in each exposure category. To assist in the interpretation of individuals using stimulant medications for ADHD, individuals’ country of birth were identified from the HMDC, and residential remoteness and socioeconomic status were obtained from the ABS. Parental links were generated using the WAFCGS in order to find if the parental country of birth made any difference to the results obtained using the individual’s country of birth. There were 700,466 records for the birth cohort and 699,704 parental links for mothers and fathers extracted for this study.

4.6.1 Data source for quantitative study two

The three de-identified routinely collected administrative health datasets were linked through the WADLS: i) the HMDC, ii) the MODDS, iii) WA Death Registrations, and iv) WA Birth Registrations. The details of the MODDS, Death Registrations and Birth Registrations have already been described in the quantitative study one above. The fields extracted from the data sets are also similar to the fields extracted for Study One (Table 2).

4.6.1.1 Western Australian Hospital Morbidity Data Collection (HMDC)

The HMDC was one of the core datasets routinely linked by the WADLS72 to other administrative health data, and one of the largest data collections managed by WA Health. In 2012-2013, the HMDC comprised over 21,000,000 electronic records of hospital admissions and discharges for all public and private patients in WA hospitals since 1970288. The number of records added to the HMDC increased every year in line with hospital utilisation and population growth. The HMDC was managed by the Inpatient Data Collection unit in the DoHWA. The key purpose of this data collection was to report to the Commonwealth as required by national legislation and to monitor and assess health service utilisation in WA. The data were also used for strategic
planning, performance monitoring, funding and resource allocation, epidemiological and other research.

The HMDC included all records of acute, psychiatric and day surgery hospital admissions in WA public and private hospitals. Patients attending outpatient clinics, community health services, residential care facilities and/or defence force health services were excluded from the HMDC. Patients’ countries of birth and socio-demographic information was recorded along with clinical details, such as principal diagnosis, contributing and co-existing conditions, procedures and complications, as well as hospital admission and separation dates (See Appendix IV for Hospital Inpatient Summary Form). The clinical details were recorded using the International Classification of Disease, 10th Revision (ICD-10-AM) and Australian Classification of Health interventions. In order to validate the accuracy of the information, the HMDC undertook a rigorous quality assurance program which included editing data quality; validating submitted data; standardising and auditing the coding practices; reviewing data; health service monitoring, evaluation and planning; and providing education and training where necessary. All of these procedures were designed to maintain the high quality of the data in the HMDC.

The unit record within the HMDC was an episode of care, which referred to the period of treatment to a patient from the point of hospital admission to the point of discharge from hospital. Each patient admitted to a hospital was assigned a unique de-identified HMDC ‘root number’ in order to track the same patient with multiple episodes of cares. An additional de-identified ‘LP root number’ was assigned to each patient for each specific episode of care to enable the specific admission to be studied. With the WADLS, another unique Client Identifier or Unit Medical Record Number (UMRN) was also assigned to each patient at first admission. The Client Identifier or UMRN was then used for all subsequent admissions within a particular hospital. In order to analyse patterns of admissions of each patient, linking all records pertaining to the same patient in a consecutive chain beginning with the first admission was necessary. Each newborn baby was further assigned his or her mother’s identifier or UMRN in order to provide a link between mother and baby during the birth episode. The mother’s Identifier or mother’s UMRN is a mandatory field added to the baby’s record on the birth admission only. This, together with use of name, gender and date of birth, was part of the process used within the WADLS to create probabilistic links between records.
belonging to the same patient, followed by linking to all records, including genealogical records, that matched for that patient.

The HMDC data for this research covered 725,596 individuals aged 0-25 years for the period of 1 January 1980 to 31 December 2007. The key variables included: a de-identified and encrypted patient identifier, an encrypted unique record identifier, first admission date, age at admission, sex, country of birth, Indigenous status, postcode of residence, and 1996 and 2001 SEIFA and ARIA scores.

4.6.2 Sample selection

The HMDC was used to identify all people who were admitted to any WA hospital for any reason within their first 25 years of life between 1 January 1980 and 31 December 2007. They were divided into those who had or did not have dispensed prescription stimulant records from 1 January 2003 – 31 December 2007.

4.6.3 Variable and measurements

4.6.3.1 Outcome and Exposure variables

Similar to study one, the outcome, dispensing of prescription stimulant medication, was defined as having at least one record of a prescribed stimulant dispensed at any time between 1 January 2003 and 31 December 2007. The definitions and procedures for exposure variables such as residential remoteness, socioeconomic status, sex and Indigenous status were essentially the same as described in study one.

Age

The age of each individual was recorded ‘in years’ in the HMDC datasets for each hospital admission. The age of each individual at first hospital admission within the first 25 years of life between 1980 and 2007 was extracted from the value of age in the age variable. Individuals’ date of birth available in the MODDS dataset was used to calculate the age at first record of stimulant medication between 2003 and 2007, as was done in Study One.
Country of birth

While country names were available for country of birth variable in the birth registration data, country codes were recorded in the HMDC. The country codes were mapped using the ABS: Standard Australian Classification of Countries 2011 (SACC-2011) (Table 4). Where some country codes were unavailable in SACC-2011, the nearest equivalent code was mapped from the ABS: Standard Australian Classification of Countries for Social Statistics 1990 (ACCSS 1990), and the ABS: Standard Australian Classification of Countries 1998 (SACC-1998). For example, 913 former Yugoslavians were back-mapped from ASCCSS-1990 to match the country code 3206 in SACC-2011; similarly the country code 902 for Victoria, and 906 for Tasmania in SACC-1998 were mapped as country code 1101 for Australia in SACC-2011. More than 92% of the cohort population was born in Australia.

Similar to Study One, countries of birth were grouped into sub-region and region, and then were further aggregated into LPNO and HPNO countries based on a preliminary analysis (Figure 11) in order to compare stimulant use based on the individual’s LPNO and HPNO status.

4.6.3.2 Exclusions

Individuals, who had a record in the MODDS, but not in the HMDC, were excluded. Children, adolescents and young adults who were born before 1980 or first admitted into a hospital at an age more than 25 years were excluded. Individuals who died before 2003 (n=5,252) were also excluded as there was no possibility of ascertainment of an outcome.
Table 4. Mapping country of birth according to Australian Bureau of Statistics

<table>
<thead>
<tr>
<th>Region</th>
<th>Sub-Region</th>
<th>SACC* - 2011</th>
<th>SACC* - 1998</th>
<th>ASCCSS† - 1990</th>
</tr>
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<tbody>
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<td>Central and West Africa</td>
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<td>9000, 9127-9128</td>
<td></td>
</tr>
<tr>
<td></td>
<td>North Africa</td>
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<td>4000, 4199</td>
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</tr>
<tr>
<td></td>
<td>Southern and East Africa</td>
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<td></td>
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<td>Central Asia</td>
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<td>5000, 5106-5108</td>
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</tr>
<tr>
<td></td>
<td>East Asia</td>
<td>6100-6105</td>
<td>6106-6108</td>
<td></td>
</tr>
<tr>
<td></td>
<td>South Asia</td>
<td>7100-7107</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>South East Asia</td>
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<td>4109-4110, 5106-5108</td>
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<td>British Isles/United Kingdom, Channel Islands</td>
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<td></td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td>South Eastern Europe</td>
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<td>2600, 2605-2608, 2609, 2611, 2614</td>
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<td></td>
<td>3311, 3312</td>
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<td></td>
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<td></td>
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<td>2309, 2310</td>
<td>2207-2209, 2211</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2311</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Middle East</td>
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<td>3000, 3109-3114</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Northern America</td>
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<td>7000</td>
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<td></td>
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<td>901-909, 1103-1109, 1710</td>
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<td></td>
<td>New Zealand</td>
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<td></td>
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<td>8000, 8105-8106, 8111, 8114, 8313, 8316</td>
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</tr>
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</tr>
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<td>0, 1, 3</td>
<td>0, 1, 3</td>
<td>0, 1, 3</td>
</tr>
</tbody>
</table>

*SACC – Standard Australian Classification Countries
†ASCCSS – Australian Standard Classification of Countries for Social Statistics
Figure 11. Distribution of stimulant medication among individuals admitted into hospitals from 1980-2007, by region and sub-region

Abbreviations: CAAC = Central America and the Caribbean, ME = Middle East, NA = North America, SA = South America, UK = Unknown
4.7 STATISTICAL ANALYSIS FOR QUANTITATIVE STUDY ONE & TWO

In study one the analyses were restricted to individuals with a WA Birth Registration and who had parental identities available in the WAFCGS. In the second study, individuals who were no more than 25 years of age at the time of hospital admission were selected for analysis. In both studies, descriptive statistics were performed for all study variables with summary statistics, including means and standard errors obtained for continuous variables, and frequencies and percentages for categorical variables. Univariate and multivariate binary logistic regression models, as well as Cox proportional hazards regression models containing terms for LPNO/HPNO status, Aboriginal/non-Aboriginal, age at dispensed prescription stimulants, sex, residential remoteness and socioeconomic status were used to examine factors associated with stimulant use. Multiple linear regression models were also fitted to compare mean ages of individuals at initial stimulant use during 2003 and 2007. Missing values for each variable were entered as a separate exposure category of ‘unknown’ in order to include all subjects in the analyses. Statistical significance was set to p<0.05. SPSS version 21.025\textsuperscript{293} was used for all analysis.

4.8 CHAPTER SUMMARY

In this chapter the methodology for quantitative study one and study two using WADLS and WAFCGS was described in detail. Data sources and outcome and exposure variables including defining country of birth were discussed. The findings from Study One are presented as manuscripts in the subsequent Chapters 5 and 6, and from Study Two in Chapter 7.
EXPLORING PARENTAL COUNTRY OF BIRTH DIFFERENCES IN THE USE OF PSYCHOSTIMULANT MEDICATIONS FOR ADHD: A WHOLE-POPULATION LINKED DATA STUDY

This is an exact replication of the journal publication, albeit formatted for the thesis

5.1. ABSTRACT

Objective: To explore parental country of birth differences in the use of stimulants for attention deficit hyperactivity disorder (ADHD) in Western Australian (WA) children and adolescents.

Methods: Statutory WA stimulant notification and dispensing records from 2003-2007 were linked to whole-population state data from 1980 to 2007. Parental attributes were obtained through the WA Family Connections genealogical linkage system. Using multivariate logistic and linear regression, the differences in WA stimulant use for ADHD by parental country of birth, socioeconomic status and geographical remoteness were examined.

Results: Of 671,231 people born in WA between 1980 and 2007, 13,555 (2%) used stimulants for ADHD. Of these, 734 (5%) had parents born in Africa, Asia, Middle-East or South America, and 12,006 (87%) had parents born in Australia, North America and Europe. Children and adolescents with parents born in traditionally non-Anglophonic countries were less likely to be treated with stimulants (OR=0.17, 95% CI 0.14-0.21) than those with parents born in Anglophonic countries. Socioeconomic advantage and residential remoteness were also significant independent predictors of a decreased likelihood of stimulant use.
Conclusions: The results highlight the importance of improving knowledge about cultural differences in access to and attitudes towards the diagnosis of ADHD and different approaches to its treatment.

5.2. INTRODUCTION

Stimulants are the most widely prescribed medication in children and adolescents for the treatment of attention deficit hyperactivity disorder (ADHD)\textsuperscript{21}. Their use has been steadily increasing in developed countries like the US\textsuperscript{21} and Australia\textsuperscript{24}. There is evidence supporting the efficacy and cost-effectiveness of stimulants in the management of ADHD\textsuperscript{188-189}. However, concerns have been raised about the risk of long-term stimulants dependence, their use for inappropriate reasons, and the safety of exposure to these medications in developing children, including possible cardiovascular complications\textsuperscript{34-37}.

The past two decades have seen large variations in dispensed prescriptions of stimulant medication in Western Australia (WA). From 1989 to 2000, 85-90\% of the 20,648 West Australians on prescription stimulants were children\textsuperscript{25}. The proportion of children on stimulant medication peaked in 2002 at 2.6\% per capita\textsuperscript{294}, before it declined by one-third between 2004 and 2010, following the inception of the Statutory Stimulant Regulatory Scheme in mid-2003 pertaining to all prescribing of these medication in the state\textsuperscript{215}. In 2011, there were 15,096 patients receiving prescribed stimulants, with 39\% of them being children – an increase of 6\% from 2010\textsuperscript{215}. These temporal variations have engendered considerable controversy among some policy makers and clinicians about potential over or under of stimulant medication for children with ADHD\textsuperscript{294}. In addition, regional prescribing variations and higher rates of stimulant medication use for treatment of ADHD in lower socioeconomic areas in WA have been reported\textsuperscript{45}.

Despite the polarisation of opinion regarding the prescribing patterns over time, little or no attention has been paid to the diagnosis and treatment of the condition in children with different racial and ethnic backgrounds in Australia. In the US, the occurrence and treatment of the condition has been found to vary with insurance status\textsuperscript{50}, family structure\textsuperscript{49} and geographic and demographic factors\textsuperscript{46}, yet we know little about the possibility of such variations in Australia, where there is stronger policy support for universal access to health. Culture can influence parents’ understanding and
interpretation of child behaviour and development. Parents’ interpretation of child behaviour may influence clinical decisions, because reports from parents are commonly used in the comprehensive assessment leading to a ADHD diagnosis. Consequently, it is important to determine variations in the prescribing of stimulant medication within different sections of the population, including different ethnic groups.

This study explores disparities in the use of stimulant medication for the treatment of ADHD in WA across parental country of birth and other socio-demographic factors.

5.3. METHODS

5.3.1. Data sources

We used de-identified whole-population linked data that are routinely collected and maintained by WA Department of Health (DoH). A retrospective cohort of children, adolescents and young adults born in WA from 1980 to 2007, and identified from registered birth certificates, was linked to the prescription of stimulant medication dispensed for ADHD only between 2003 and 2007, identified from statutory stimulant notification and stimulant dispensing records maintained by the DoH. Birth registrations were used to define parent–child relationships as well as determine each parent’s country of birth. Midwife records were also linked to the birth registration to verify the relationships between mothers and children. Moreover, mother’s age on the date of delivery was ascertained from the midwife records because the birth registrations captured mother’s age at the time the birth was registered.

Scores for residential and socioeconomic disadvantage were derived from the Accessibility/Remoteness Index of Australia (ARIA) and the Index of Relative Socio-Economic Disadvantage (IRSD), using mother’s address recorded on the midwife forms. ARIA scores were grouped into three levels: metropolitan, rural and remote. The IRSD provides an area-based measure of social disadvantage for each person in the data. This metric is allocated based on Collection Districts of 220 households and is used as a means to control for socioeconomic status. IRSD scores were grouped into five levels of socioeconomic disadvantage: least disadvantaged (75%+ percentile of the population), less disadvantaged (50-74%), little disadvantaged (25-49%), more disadvantaged (10-24%) and most disadvantaged (lowest 10%).
5.3.2. Analytic approach

Parental country of birth was classified according to the Human Relations Area Files known as eHRAF World Cultures, an anthropological database that contains information on most aspects of cultural and social life, and classifies cultures into eight major geographical regions: Asia, Europe, Africa, North America, the Middle East, Oceania (including Australia and New Zealand), Central America and the Caribbean, and South America. We combined Central America and the Caribbean and South America into one category, referred to as ‘South America’. Because the majority of parents were born in Australia, which according to the eHRAF fell under Oceania, we referred to this category as Australia and New Zealand.

We further aggregated parental country of birth into Lower Propensity National Origin (LPNO) and Higher Propensity National Origin (HPNO) countries, based on a preliminary analysis that examined other national groupings of sub-regions (such as Central Africa, Northern Africa, Southern Africa, Western Africa etc.) classified by the eHRAF database. Our preliminary results showed a tendency for reduced stimulant use for ADHD in individuals with parents born in Africa, Asia, the Middle East or South America (thus the LPNO countries), compared with individuals with parents born in Australia or New Zealand, Europe or North America (the HPNO countries). Thereafter we relied on a comparison between parental countries of birth based on the LPNO/HPNO status of each mother and father. The numbers were too few for a less aggregated analysis at the individuals’ parent level.

5.3.3. Statistical analysis

We measured the use of stimulant medication using the binary outcome of having at least one record of stimulant prescription dispensed at any time during 2003 and 2007. Crude and multivariate logistic regression models were used, with adjusted models controlling for a range of socio-demographic and clinical characteristics to examine factors associated with stimulant medication use for the treatment of ADHD in the entire birth cohort. Adjustment for mother’s age as a continuous covariate was performed using a Box-Tidwell transformation. Multiple linear regression was used to compare unadjusted and adjusted mean ages in the individuals who were prescribed a stimulant medication for the first time.
Parents who identified themselves as Aboriginal, Torres Strait Islander and/or Pacific Islanders were excluded from our analysis. However, due to small relative numbers the results were essentially the same (OR=0.55, 95% CI 0.34-0.87) when Aboriginal parents were included. Even though the Aboriginal parents were born in Australia, their perception of mental or behavioural disorder could be different from the perception of non-Aboriginal Australian parents\(^{260}\). It is beyond the scope of this article to discuss Aboriginals’ attitude and beliefs towards ADHD.

5.3.4. Ethics approval

The study was approved by the Human Research Ethics Committee of the University of WA and the WA DoH Human Research Ethics Committee.

5.4. RESULTS

5.4.1. Observed differences in stimulant use

A total of 13,555 (2.0%) children and adolescents of the 671,231 cohort who were born in WA in 1980-2007 were prescribed stimulant medication for ADHD treatment between 2003 and 2007. The characteristics of the study participants are shown in Table 5. The mean age at first stimulant use was 13 years (SD=5 years). More than half (N=6910, 51%) were children aged 5-12 years, and 1% (N=175) were children less than 4 years old (data not shown), and 77% were male. The majority of the ADHD individuals (88.6%) had HPNO parents born in Australia, Europe or North America while a much smaller proportion (5.4%) had one or both LPNO parents born in Africa, Asia, the Middle East or South America. More than 67% lived in the metropolitan area, 15% in rural and 4% in remote areas. More than two-fifths of the individuals (41%) came from the least socioeconomic disadvantaged group. More than one-fifth (21%) were classified as less disadvantaged, nearly 10% little disadvantaged, about 5% more disadvantaged and 11% were in the most disadvantaged group, while 12% had information unknown.
Table 5. Characteristics of the participants in the study

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>No ADHD (%)</th>
<th>ADHD (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants</td>
<td>657,676</td>
<td>13,555</td>
</tr>
<tr>
<td>Mean Age in Years (SD)</td>
<td>13 (5)</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>334,076 (50.8)</td>
<td>10,475 (77.3)</td>
</tr>
<tr>
<td>Female</td>
<td>323,577 (49.2)</td>
<td>3,080 (22.7)</td>
</tr>
<tr>
<td>Unknown</td>
<td>23 (0.01)</td>
<td>0</td>
</tr>
<tr>
<td>Parents’ PNO Status</td>
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<td></td>
</tr>
<tr>
<td>HPNO parents</td>
<td>552,134 (84.0)</td>
<td>12,006 (88.6)</td>
</tr>
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<td>Mother only LPNO</td>
<td>24,379 (3.7)</td>
<td>273 (2.0)</td>
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<td>Father only LPNO</td>
<td>18,512 (2.8)</td>
<td>325 (2.4)</td>
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<td>Both LPNO parents</td>
<td>33,259 (5.1)</td>
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<td>Residential Remoteness</td>
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<td>Metropolitan Western Australia</td>
<td>420,256 (63.9)</td>
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</tr>
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<td>Rural Western Australia</td>
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<td>Socioeconomic Disadvantage</td>
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<tr>
<td>Little disadvantaged</td>
<td>56,170 (8.5)</td>
<td>1,288 (9.5)</td>
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<tr>
<td>More disadvantaged</td>
<td>27,591 (4.2)</td>
<td>625 (4.6)</td>
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<tr>
<td>Most disadvantaged</td>
<td>52,926 (8.0)</td>
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<td>Unknown</td>
<td>85,296 (13.0)</td>
<td>1,656 (12.2)</td>
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</table>

5.4.2. Differences in the effects of parental country of birth and family characteristics on stimulant use

Crude and adjusted odds ratios pertaining to stimulant medication use obtained from logistic regression for the LPNO status of the individual’s mother and father, and each residential remoteness and socioeconomic disadvantage category are shown in Table 6. Results for the adjusted model were similar to the crude results and indicated that individuals with two LPNO parents had 83% lower odds (OR 0.17, 95% CI 0.14-0.21) of having prescribed stimulants, compared to individuals with two HPNO parents. Individuals with a LPNO father had 47% lower odds (OR 0.53; 95% CI 0.47-0.61), while individuals with a LPNO mother had 19% lower odds (OR 0.81; 0.72-0.91) compared to individuals with two HPNO parents.
Table 6. Differences in stimulant use associated with parental country of birth and family characteristics

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<th>Adjusted</th>
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<td>p-value</td>
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<td>&lt;0.001</td>
<td>0.81 (0.72-0.91)</td>
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<td>Father only LPNO</td>
<td>0.52 (0.46-0.58)</td>
<td>&lt;0.001</td>
<td>0.53 (0.47-0.61)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Both LPNO parents</td>
<td>0.19 (0.16-0.22)</td>
<td>&lt;0.001</td>
<td>0.17 (0.14-0.21)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Mother’s age</td>
<td>1.24 (0.94-1.62)</td>
<td>0.12</td>
<td>0.98 (0.71-1.36)</td>
<td>0.91</td>
</tr>
<tr>
<td>Residential Remoteness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>0.88 (0.83-0.92)</td>
<td>&lt;0.001</td>
<td>0.77 (0.73-0.81)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Remote</td>
<td>0.66 (0.60-0.72)</td>
<td>&lt;0.001</td>
<td>0.65 (0.60-0.72)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Socioeconomic Disadvantage</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Least disadvantaged</td>
<td>1.07 (1.02-1.12)</td>
<td>&lt;0.006</td>
<td>1.04 (1.00-1.10)</td>
<td>0.07</td>
</tr>
<tr>
<td>Less disadvantaged</td>
<td>1.20 (1.13-1.28)</td>
<td>&lt;0.001</td>
<td>1.14 (1.06-1.21)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>More disadvantaged</td>
<td>1.19 (1.09-1.29)</td>
<td>&lt;0.001</td>
<td>1.14 (1.04-1.25)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Most disadvantaged</td>
<td>1.46 (1.38-1.55)</td>
<td>&lt;0.001</td>
<td>1.45 (1.36-1.54)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Individuals born to mothers in rural and remote areas were significantly less likely to be exposed to stimulant medication compared with metropolitan residents, with greater reductions in the likelihood of stimulant medication treatment as remoteness category increased (Table 6). Those from the little, more and most disadvantaged areas had significantly increased odds of stimulant medication use compared with their less disadvantaged counterparts.

The mean age of initial treatment with stimulant medication for those with a LPNO father was almost one year older than those with a HPNO father (13.31 vs. 12.48 years after adjustment, p<0.001; Table 7). Although individuals with a LPNO mother also tended to be older at first use of stimulant medication, this difference was less marked. Individuals from the least disadvantaged socioeconomic areas were between 1.36 and 0.93 years older at the time of first use of stimulant medication compared with more disadvantaged individuals; whereas there was an inconsistent pattern of results for age at first use according to residential remoteness.
5.5. DISCUSSION

Our results show that individuals who had parents born in traditionally non-Anglophonic, non-European regions such as Africa, Asia, the Middle East or South America were significantly less likely to be treated with stimulant medication compared with those whose parents were born in Australia, Europe or North America. This association was stronger when the father was born in a LPNO country than when the mother was. ADHD individuals with a LPNO father also displayed a significant tendency to be older at the time of first stimulant use.

These findings of cultural disparities in stimulant use are consistent with another study and could be explained by cultural differences in the expectation, diagnosis and treatment of behaviours associated with ADHD. O’Mahony and Donnelly emphasised the cultural norms and health attitudes that immigrants bring with them from their homelands, stressing that culture shapes immigrants’ responses to health and illness and provides a coping mechanism for their mental health. Subsequently, culture plays a big role in determining how parents internalise and respond to their child’s behaviour, and in their beliefs about appropriateness of medication for behaviour problems. Parents perceive their child’s behaviour based on their own cultural upbringing, their attitudes about behavioural problems, and their beliefs about the appropriateness and effectiveness of pharmacotherapy.

Parents in Confucian culture are expected to take personal responsibility for their child’s behaviours and this may induce reservations about the use of medication. African-American parents have a socially constructed view of ADHD and are less likely to view a child’s behaviour as pathological. Subsequently, the African-American parents were found to exhibit reduced faith in medical professionals and a generally negative perception of ADHD treatment with medication, which in one study apparently acted as a barrier to using ADHD treatment services. Similarly Iranian parents were reported to not consider the behaviours associated with ADHD symptoms as pathologic, but instead to regard these behaviours as ‘mischievous acts’ or a ‘natural behavioural stage of childhood development’. The researchers in that instance noted that parents’ fear of embarrassment with the stigma of mental illness and psychiatric treatment were reasons for delaying treatment in Iranian culture.
Table 7. Comparing patient mean age at first stimulant used

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Unadjusted</th>
<th></th>
<th>Adjusted</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean age (yrs)</td>
<td>Mean difference in year (95% CI)</td>
<td>p-value</td>
<td>Mean age (yrs)</td>
<td>Mean difference in year (95% CI)</td>
</tr>
<tr>
<td>Mother</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HPNO*</td>
<td>12.71</td>
<td></td>
<td></td>
<td>12.19</td>
<td>0.32 (-0.19, +0.84)</td>
</tr>
<tr>
<td>LPNO</td>
<td>13.44</td>
<td>0.73 (0.25, 1.20)</td>
<td>&lt;0.003</td>
<td>12.52</td>
<td>0.32 (-0.19, +0.84)</td>
</tr>
<tr>
<td>Father</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HPNO*</td>
<td>12.79</td>
<td></td>
<td></td>
<td>12.48</td>
<td>0.83 (0.34, 1.32)</td>
</tr>
<tr>
<td>LPNO</td>
<td>13.86</td>
<td>1.07 (0.62, 1.52)</td>
<td>&lt;0.001</td>
<td>13.31</td>
<td>0.83 (0.34, 1.32)</td>
</tr>
<tr>
<td>Residential Remoteness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolitan*</td>
<td>12.85</td>
<td></td>
<td></td>
<td>12.52</td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>11.82</td>
<td>-1.03 (-1.27, -0.80)</td>
<td>&lt;0.001</td>
<td>11.77</td>
<td>-0.74 (-0.98, -0.51)</td>
</tr>
<tr>
<td>Remote</td>
<td>13.06</td>
<td>0.21 (-0.21, 0.62)</td>
<td>0.329</td>
<td>12.77</td>
<td>0.26 (-0.16, 0.67)</td>
</tr>
<tr>
<td>Socioeconomic Disadvantage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Least disadvantaged*</td>
<td>13.32</td>
<td></td>
<td></td>
<td>13.27</td>
<td></td>
</tr>
<tr>
<td>Less disadvantaged</td>
<td>12.28</td>
<td>-1.04 (-1.26, -0.83)</td>
<td>&lt;0.001</td>
<td>12.34</td>
<td>-0.92 (-1.14, -0.71)</td>
</tr>
<tr>
<td>Little disadvantaged</td>
<td>11.93</td>
<td>-1.40 (-1.70, -1.10)</td>
<td>&lt;0.001</td>
<td>12.06</td>
<td>-1.20 (-1.50, -0.91)</td>
</tr>
<tr>
<td>More disadvantaged</td>
<td>11.76</td>
<td>-1.56 (-1.96, -1.16)</td>
<td>&lt;0.001</td>
<td>11.91</td>
<td>-1.36 (-1.76, -0.96)</td>
</tr>
<tr>
<td>Most disadvantaged</td>
<td>11.97</td>
<td>-1.35 (-1.63, -1.08)</td>
<td>&lt;0.001</td>
<td>12.2</td>
<td>-1.07 (-1.35, -0.79)</td>
</tr>
</tbody>
</table>

*Reference category
Similarly, Latino parents feared a stigma attached to medication use for ADHD and as a result delayed its treatment\textsuperscript{165}, while Indian parents were reluctant to accept what they perceived as a psychiatric label for their child’s behaviour and were more likely to pursue non-pharmacological approaches such as behaviour management, educational and religious treatments, instead of stimulant medication\textsuperscript{242}.

There is some evidence to suggest that mothers tend to rate levels of ADHD symptoms as more serious than fathers, and also that fathers are more likely to perceive erratic or difficult behaviours as a normal part of child development, especially in relation to their sons\textsuperscript{295}. This has been advanced as a possible reason why fathers may be more resistant to ADHD diagnosis and drug treatment. Our results suggest that having a LPNO father, in particular, reduces the likelihood or at least delays the onset of stimulant use for ADHD, which may support these suggestions, and in South-Asian countries there is evidence that fathers are the dominant decision maker on child health issues and the related costs of any health problems\textsuperscript{297}. Short-acting dexamphetamine was the only psychostimulant available through Australia’s Pharmaceutical Benefits Scheme (PBS) until long-acting methylphenidate became subsidized on the PBS around mid-2007\textsuperscript{24}. As such it is possible that the substantial costs that applied if individuals were not treated with dexamphetamine may have discouraged people from LPNO countries and with lower socioeconomic background to agree to stimulant medications for their children.

Individuals in the metropolitan area had significantly higher exposure to stimulant medications than individuals living in rural or remote areas. This is consistent with other data, indicating that stimulant prescribing rates in major cities are 2.3 to 5.3 times greater than in remote areas\textsuperscript{45}. The effect is possibly due to geographic disparities in access to specialised health care. In WA, only registered paediatricians, psychiatrists or neurologists are approved to initiate treatment with stimulant medication\textsuperscript{298}. However, explanations related to attitudes and lifestyles are also a possibility. Potentially, the threshold for the perception of abnormal behaviour is lower in an urbanised city environment with a greater density of population.

Our result that socioeconomically disadvantaged individuals had an increased rate of stimulant use is partly consistent with a study in the US, where disadvantaged children
were observed to be more likely to meet the diagnostic criteria for ADHD, yet less likely to receive regular medication. It is possible that in Australia, the greater national policy support for universal access to healthcare is able to remove sufficient structural barriers to allow the normative and expressed needs for ADHD treatment to move empirically in the same direction.

The findings of our study suggest the need for outreach services to parents of children and adolescents with ADHD from LPNO countries. These groups should be protected from being inappropriately diagnosed or over diagnosed for ADHD, but at the same time they must have access to appropriate services that are likely to be of benefit. In order to address the LPNO group’s needs, medical professionals and educators should recognise the relevant cultural cues, and acknowledge the differences between behaviour disorder and cultural variation through appreciation and culturally appropriate manners. Further the findings provide a lead for additional research that might inform a wider and more effective range of interventions for ADHD – not necessarily to replace medication, but to complement it.

5.6. LIMITATIONS

While the results of this analysis are consistent with the findings from a number of previous studies, some limitations must be considered. First, ethnicity information could not be obtained. Therefore, we relied on parental country of birth information recorded on birth and midwife records for parental ethnic identity. Although country of birth may be expected to influence people’s perceptions and beliefs, it is possible that in some instances reliance on the country of birth information masked people’s true ethnic identity. For instance, some parents who were born in South Africa, and thus classified as LPNO in this study, may have better fitted in the HPNO classification, due to their European ethnic background. These limitations in the measurement of parental ethnic identity may have influenced the findings of the analysis.

Second, some LPNO parents were likely to have been newly arrived migrants to Australia, and may have faced a number of challenges in accessing healthcare due to a lack of knowledge about available services, linguistic barriers and financial difficulties, compared with LPNO parents who have lived in Australia for some time. However, due to the absence of data we could not evaluate parents’ length of stay in Australia. It
is possible that the additional challenges for the new migrants created a barrier to accessing ADHD services and thus may have influenced the results. In spite of that, we suspect that it is the culturally embedded values and expectation of behaviours that mostly determines LPNO parents’ help seeking and access to care for ADHD. In a cross cultural study immigrants are noted to be governed by their own cultural attitudes towards health and healthcare regardless of length of stay in a host country.\textsuperscript{299}

Finally, we are confident about the generalisability of our analytic findings on associations with stimulant medication use Australia-wide, given that the WA population is representative of Australia as a whole.\textsuperscript{300} However, it should be noted that the use of stimulant treatment across Australia varies and so purely descriptive results, such as the 2% birth cohort exposure, may vary between Australian jurisdictions.

\textbf{5.7. CONCLUSION}

Children and adolescents who had parents born in African, Asian, Middle Eastern or South American countries were less likely to use stimulant medication for the treatment of ADHD compared with those with parents born in Australia, New Zealand, Europe or North America. Father’s birthplace seemed to be particularly influential in reducing and delaying stimulant use in people from traditionally non-Anglophonic countries. We also observed differences in stimulant use across socioeconomic groups and remoteness areas. Our findings highlights the importance of understanding differences in both culture and ease of access in relation to stimulant prescribing patterns for ADHD treatment.

Future research examining the cultural influences on ADHD treatment should include a qualitative approach to explore the parental country of birth differences in attitude towards ADHD and its treatment, as well as financial and spatial barriers to access. It could also investigate if parental country of birth influences the stimulant medication use according to the gender of the child. Such research may shed light on whether over-prescribing or under-prescribing of stimulant medication is occurring within certain cultural groups and this may lead to possible avenues for alternative therapeutic approaches or improved accessibility to pharmacotherapy where this is warranted.
6.1 ABSTRACT

**Background:** Increasing recognition of Attention Deficit/Hyperactivity Disorder (ADHD) among Aboriginal children, adolescents and young adults is a public health challenge. We investigated the pattern of prescription stimulants for ADHD among Aboriginal individuals in Western Australia (WA).

**Methods:** Using a whole-population-based linked data we followed a cohort of individuals born in WA from 1980-2005, and their parents were born in Australia, to identify stimulant prescription for ADHD derived from statutory WA stimulant prescription dispensing between 2003 and 2007. Parental link was ascertained through WA Family Connections Genealogical Linkage System. Cox proportional hazards regression (HR) models were performed to determine the association between stimulant use and Aboriginal and non-Aboriginal status.

**Results:** Of the total cohort of 186,468, around 2% (n=3677) had prescription stimulants for ADHD. Individuals with both Aboriginal parents were two-thirds (HR 0.33, 95%CI 0.26-0.42), and with only Aboriginal mother were one-third (HR 0.69, 95%CI 0.53-0.90) less likely to have stimulants, compared to individuals with non-Aboriginal parents. HR in Aboriginals was 62% lower (HR 0.35, 95%CI 0.25-0.49) in metropolitan areas, and 72% lower (HR 0.28, 95%CI 0.20-0.38) in non-metropolitan areas, than non-Aboriginals. The risk for stimulant use was four times higher among Aboriginal boys than Aboriginal girls (HR 4.08, 95%CI, 2.92-5.69).
Conclusion: Aboriginal cultural understanding of ADHD and attitude towards stimulant medication serve as a determinant of their access to health services. Any ADHD intervention and policy framework must take into account a holistic approach to Aboriginal culture, beliefs and individual experience to provide optimal care they need.

6.2 BACKGROUND

Attention Deficit/Hyperactivity Disorder (ADHD) has been defined as a common childhood-onset neurodevelopmental disorder characterized by severe inattention, impulsivity and hyperactivity which can be associated with significant educational and social impairment. Psychostimulant medications such as methylphenidate and dexamphetamine are often recommended as a first-line modality for treating ADHD. Despite extensive research into factors contributing to ADHD, the aetiology and pathogenesis of the condition are poorly understood. It may be influenced by a combination of genetic and environmental factors. As is true with most mental and developmental disorders, there is not a definitive test for ADHD, because diagnosis and classification primarily rely on observed or self-reported behaviours. Moreover, the interpretations of the severity of those behaviours and whether they should be described as abnormal are subjective.

In Australia, there has been an increasing recognition of ADHD symptoms among Aboriginal children and adolescents than those in the non-Aboriginal population. Zubrick et al. identified 15% Aboriginal children compared to 9.7% non-Aboriginals at the same age were at high risk of clinically significant hyperactivity. Yet, we do not have a clear understanding of the determinants that may account for this disparity. People with ADHD are over-represented in criminal justice system, and the rates of incarceration are reported high among Aboriginal young. The prevalence of ADHD is higher among people living in low socioeconomic condition. It is well established that Aboriginal children are socially and economically disadvantaged with a lower life expectancy and less than equal opportunity. Whether the higher manifestation of ADHD symptom in Aboriginal children and adolescents is a true prevalence of clinical ADHD, or their unique learning and behavioural patterns that may erroneously lead to ADHD diagnosis pause a question.
There remains a dearth of research examining the degree to which ADHD behaviour is perceived as a problem and stimulant treatment is sought for ADHD in Aboriginal communities. Considerable differences exist in the perception of wellness and illness between Aboriginal and non-Aboriginal Australians. Aboriginals place a holistic concept of mental illness including culture and spirituality, family and community kinships, historical, social and economic factors, fear, education and loss which may construct a different attitude towards Western biomedical diagnostic labels and treatment for ADHD behaviour to that of mainstream Australians. This study reports the first whole-population-based Australian study of prescription stimulant pattern for ADHD among Aboriginals. In this paper the term “Aboriginal” encompasses both Aboriginal and Torres Strait Islanders as was approved as appropriate to use in scientific publications.

6.3 METHODS

6.3.1 Study population

The study population comprised a retrospective cohort of all children, adolescents and young adults who were born in WA from 1980-2005, and their parents were born in Australia, and were stratified by their parents’ Aboriginal and non-Aboriginal status. The cohort was then followed through to identify their first commencement of prescription stimulant for ADHD between 2003 and 2007. Records for still-births, parents born overseas, unknown/missing Aboriginal identity and death before 2003 were excluded, leaving 186,468 individuals for analysis. The selection criteria and process are shown in Figure 12.

6.3.2 Data Sources

Data were extracted from the WA Register of Birth, Death Registry, Midwives’ Notification System (MNS) and Monitoring of Drugs of Dependence Systems through WA Data Linkage System which links databases using probabilistically matching techniques, and is known to achieve high level of linkage sensitivity (95-99%) and specificity (98-99%). The WA Family Connections Genealogical Database was linked to ascertain parent-child relationships.
6.3.3 Variables and measurements

The outcome measure was at least one record of prescription stimulant (methylphenidate and/or dexamphetamine) dispensing for ADHD at any time during 2003-2007. Data was collected on a range of demographic factors including sex, Aboriginality, geographical remoteness, socioeconomic disadvantage and mother’s age. Parents’ Aboriginal status based on self-identification was derived from birth registry and MNS. The birth registry collects Aboriginal status of both parents, while the MNS collects information of the mothers only. Parents were recorded in birth registry as ‘Aboriginal’ ‘Aboriginal/TSI’, ‘Torres Strait Islander’, ‘Yes Aboriginal’, ‘Not Aboriginal’, ‘unknown’, and MNS data was coded as ‘Aboriginal/TSI’, ‘Caucasian’ and ‘other’. For this analysis all ‘Aboriginal’ and ‘Torres Strait Islander’ records were referred to as Aboriginal; and ‘Caucasian’, ‘Not Aboriginal’ and ‘other’ records as non-Aboriginal. As Aboriginal people are known to be under-identified, parents was considered Aboriginal if they had at least one record showing as an Aboriginal/or Torres Strait Islander in either birth registry or MNS datasets. As such, a parent, identified as Aboriginal in one dataset and non-Aboriginal in the other, was considered as Aboriginal to maximise reporting of Aboriginal people in this study.

Geographical remoteness was measured using the Accessibility/Remoteness Index of Australia (ARIA) of the Australian Census, using whichever of the 1996, 2001 or 2006 indices were closest to the year of cohort entry. ARIA scores were grouped into three levels: metropolitan, rural and remote, with metropolitan used as the reference category indicating high accessibility according to residential postcode at the time of birth. Socioeconomic disadvantage was ascertained according to the Index of Relative Socio-Economic Disadvantage (IRSD), a summary measure of Socio-Economic Indexes for Areas (SEIFA) that focused on disadvantage in terms of accessibility to education, employment and income. The IRSD scores were then groups into quintiles ranging from most disadvantaged to least disadvantaged. Similar to ARIA, SEIFA score was derived from the national census years 1996, 2001, or 2006, using the index closest to the time of birth.
Figure 12. Aboriginal and non-Aboriginal cohort identification, group selection and exclusion criteria

### 6.3.4 Statistical analysis

Descriptive statistics were calculated for all baseline demographic characteristics of the study sample, stratified by stimulant use group. The associations between stimulant use and potential predictors including gender, age, Aboriginality, geographical remoteness and socioeconomic disadvantage were investigated using univariate and multivariate Cox proportional hazards regression models with a follow-up time 31 of December 2007. Multiple linear regression models were also fitted to compare ages of individuals at initial stimulant use during 2003-2007. A two-sided p-value of <0.05 was considered statistically significant in all analyses. Missing values for each variable were entered as a separate exposure category in order to include all subjects in the analyses. Statistical analyses were performed with SPSS statistical software version 21.0.
6.3.5 Ethics approval

The study protocol adhered to guidelines for ethical conduct of Aboriginal health research, and was approved by the WA Aboriginal Health Ethics Committee (Ref.no. 589), Human Research Ethics Committee of University of WA (Ref.no. RA/4/1/2000), and Department of Health WA Human Research Ethics Committee (Ref.no. 2008/25). As de-identified data was utilised in this study, individual consent was not required.

6.4 RESULTS

Of the total cohort of 186,468 approximately 2% (n=3677) of individuals had records of prescription stimulant for ADHD during the study period. Table 8 shows the socio-demographic profile of the stimulant and non-stimulant groups. The age at initial stimulant use ranged from 2-25 years with a mean age 8.7 years (SD 2.3). Individuals who had stimulant were mostly male (n=2946, 80.1%), with non-Aboriginal parents (n=3423, 93.1%), living in metropolitan areas (n=2212, 60.2%), and were least disadvantaged (n=1299, 35.3%). Some 155 (19.5%) individuals had at least one Aboriginal parent, represented by only an Aboriginal father in 93 instances (2.5%), only an Aboriginal mother in 62 (1.7%) and by both parents being Aboriginal in 99 (2.7%).

6.4.1 Ethnic and demographic differences in stimulant use

Results of Cox regression analysis evaluating the associations between prescription stimulant use for ADHD and Aboriginality and other demographic characteristics are shown in Table 9. Both univariate and multivariate models showed that individuals with both Aboriginal parents were two-thirds less likely (adjusted HR 0.33, 95%CI 0.26-0.42, p<0.001) and individuals with Aboriginal mothers only were one-third less likely (adjusted HR 0.69, 95%CI 0.53-0.90, p=0.006) to use stimulants than individuals of non-Aboriginals parents. The risk for stimulant use in individuals of Aboriginal fathers was not significantly different from individuals of non-Aboriginal parents in either the crude or adjusted analysis. After adjusted, the association between risk for stimulant use and maternal age was marked. Individuals of mothers younger than aged 20 years had a 1.5 fold (HR 1.52, 95%CI 1.33-1.74, p<0.001) increased risk for
Table 8. Baseline demographic characteristics of Aboriginal and non-Aboriginal children and adolescents born in WA between 1980 and 2005

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>No stimulant used (%)</th>
<th>Stimulant used for ADHD (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants</td>
<td>182791</td>
<td>3677</td>
</tr>
<tr>
<td>Parents Aboriginal status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Aboriginal parents</td>
<td>164290 (89.9)</td>
<td>3423 (93.1)</td>
</tr>
<tr>
<td>Both parents Aboriginal</td>
<td>10737 (5.9)</td>
<td>99 (2.7)</td>
</tr>
<tr>
<td>Only father Aboriginal</td>
<td>3955 (2.2)</td>
<td>93 (2.5)</td>
</tr>
<tr>
<td>Only mother Aboriginal</td>
<td>3809 (2.1)</td>
<td>62 (1.7)</td>
</tr>
<tr>
<td>Mothers’ age at birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;20</td>
<td>11642 (6.4)</td>
<td>345 (9.4)</td>
</tr>
<tr>
<td>20-24</td>
<td>35823 (19.6)</td>
<td>992 (27.0)</td>
</tr>
<tr>
<td>25-29</td>
<td>60471 (33.1)</td>
<td>1157 (31.5)</td>
</tr>
<tr>
<td>30-34</td>
<td>53085 (29.0)</td>
<td>834 (22.7)</td>
</tr>
<tr>
<td>35-39</td>
<td>18764 (10.3)</td>
<td>299 (8.1)</td>
</tr>
<tr>
<td>≥40</td>
<td>2762 (1.5)</td>
<td>44 (1.2%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>244 (0.1%)</td>
<td>6 (0.2%)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>92708 (50.7)</td>
<td>2946 (80.1)</td>
</tr>
<tr>
<td>Female</td>
<td>90081 (49.3)</td>
<td>731 (19.9)</td>
</tr>
<tr>
<td>Unknown</td>
<td>2 (0.01)</td>
<td>0</td>
</tr>
<tr>
<td>Geographical remoteness</td>
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</tr>
<tr>
<td>Metropolitan</td>
<td>105567 (57.8)</td>
<td>2212 (60.2)</td>
</tr>
<tr>
<td>Rural</td>
<td>40332 (22.1)</td>
<td>799 (21.7)</td>
</tr>
<tr>
<td>Remote</td>
<td>14160 (7.7)</td>
<td>171 (4.7)</td>
</tr>
<tr>
<td>Unknown</td>
<td>22732 (12.4)</td>
<td>495 (13.5)</td>
</tr>
<tr>
<td>Socioeconomic disadvantage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Least disadvantaged</td>
<td>78304 (42.8)</td>
<td>1299 (35.3)</td>
</tr>
<tr>
<td>Less disadvantaged</td>
<td>42061 (23.0)</td>
<td>845 (23.0)</td>
</tr>
<tr>
<td>Little disadvantaged</td>
<td>17015 (9.3)</td>
<td>395 (10.7)</td>
</tr>
<tr>
<td>More disadvantaged</td>
<td>8373 (4.6)</td>
<td>183 (5.0)</td>
</tr>
<tr>
<td>Most disadvantaged</td>
<td>15467 (8.5)</td>
<td>489 (13.3)</td>
</tr>
<tr>
<td>Unknown</td>
<td>21571 (11.8)</td>
<td>466 (12.7)</td>
</tr>
</tbody>
</table>

stimulant use as compared to individuals of mothers aged 25-29 years, whereas a decreased risk was seen of mothers aged 30-34 years (HR 0.88, 95%CI 0.80-0.96, p=0.007). Boys were nearly four times more likely to be prescribed than girls (HR 3.85, 95%CI 3.53-4.20, p<0.001). Likewise, geographical remoteness was a strong determinant of the outcomes with HR ranging from 0.87 (95%CI 0.80-0.94, p<0.001) in rural to HR 0.63 (95%CI 0.54-0.74, p<0.001) in remote areas compared with HR in metropolitan areas. Individuals with most-disadvantage had a two-fold increased risk for stimulants use compared to those with least socioeconomic status (HR 2.03, 95%CI 1.82-2.27, p<0.001).
6.4.2 Comparison of stimulant use between non-Aboriginals and Aboriginals living in metropolitan and non-metropolitan areas

In the adjusted model, individuals with both Aboriginal parents were 65% less likely (HR 0.35, 95%CI 0.25-0.49, \( p<0.001 \)) in metropolitan, and 72% less likely in rural and remote areas (HR 0.28, 95%CI 0.20-0.38, \( p<0.001 \)) to have stimulants than individuals with non-Aboriginal parents (Table 10). The HR was also lower in metropolitan, (HR 0.68, 95%CI 0.48-0.95, \( p=0.03 \)) and in non-metropolitan areas (HR 0.66, 95%CI 0.44-1.0, \( p=0.05 \)) for those who had only Aboriginal mothers. A 1.6 fold higher risk for stimulant use was seen in individuals of mother’s younger than 20 years old (HR 1.56 95%CI 1.24-1.97, \( p<0.001 \)) compared with mother age 25-29 years old. The higher risk for stimulant use among boys was observed in both metropolitan (HR 3.69, 95%CI 3.33-4.09, \( p<0.001 \)) and non-metropolitan areas (HR 4.24, 95%CI 3.61-4.99, \( p<0.001 \)). HR was elevated by two-fold in the most-disadvantaged group compared with their least-disadvantaged counterparts (metropolitan – HR 2.17, 95%CI 1.89-2.49, \( p<0.001 \), (non-metropolitan– HR 1.80, 95%CI 1.49-2.17, \( p<0.001 \)).

6.4.3 Comparison of stimulant use within Aboriginal group

The fitted univariate and multivariate models for stimulant use determinants in only those individuals who had any Aboriginal parents are shown in Table 11. Aboriginal boys were four times more likely to be prescribed than Aboriginal girls (HR 4.08, 95%CI 2.92-5.69, \( p<0.001 \)). Aboriginals living in remote areas were 62% less likely (HR 0.38, 95%CI 0.26-0.56, \( p<0.001 \)) to have stimulants than their city counterparts. Mothers’ age and socioeconomic status were not significantly associated with stimulant use within this group. We also fitted a multiple linear regression model to examine the association between mean age at initial prescription stimulants and demographic and geographic variables, but no association was observed (Appendix V).
Table 9. Hazard ratios and 95% confidence intervals of prescription stimulant medication in Aboriginal and non-Aboriginal children and adolescents born in WA

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Univariate Analysis</th>
<th>Multivariate Analysis&lt;sup&gt;1&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HR (95% CI)</td>
<td>P-Value</td>
</tr>
<tr>
<td>Parents</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aboriginal status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Aboriginal parents</td>
<td>1.0</td>
<td>0.1</td>
</tr>
<tr>
<td>Both parents Aboriginal</td>
<td>0.45(0.37-0.55)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Only father Aboriginal</td>
<td>1.13(0.92-1.38)</td>
<td>0.26</td>
</tr>
<tr>
<td>Only mother Aboriginal</td>
<td>0.78(0.61-1.01)</td>
<td>0.059</td>
</tr>
<tr>
<td>Mothers’ age group in years at birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;20</td>
<td>1.54(1.36-1.73)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>20-24</td>
<td>1.44(1.32-1.56)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>25-29</td>
<td></td>
<td>1.0</td>
</tr>
<tr>
<td>30-34</td>
<td>0.82(0.75-0.90)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>35-39</td>
<td>0.84(0.74-0.95)</td>
<td>0.006</td>
</tr>
<tr>
<td>≥40</td>
<td>0.84(0.62-1.13)</td>
<td>0.24</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3.83(3.53-4.15)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Geographical remoteness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>0.95(0.87-1.03)</td>
<td>0.18</td>
</tr>
<tr>
<td>Remote</td>
<td>0.58(0.50-0.68)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Socioeconomic disadvantage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Least disadvantaged</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Less disadvantaged</td>
<td>1.21(1.12-1.32)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Little disadvantaged</td>
<td>1.39(1.24-1.56)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>More disadvantaged</td>
<td>1.31(1.12-1.53)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Most disadvantaged</td>
<td>1.88(1.70-2.09)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

<sup>1</sup>All parameters were included in the regression model so as to adjust each result for potential confounding by all other covariates.
Table 10. Comparison of prescription stimulant medication use for ADHD in Aboriginal and non-Aboriginal children and adolescents by metropolitan and non-metropolitan areas

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Metro</th>
<th>Non-Metro</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HR (95% CI)</td>
<td>P-Value</td>
</tr>
<tr>
<td>Parents Aboriginal status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Aboriginal parents</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Both parents Aboriginal</td>
<td>0.35(0.25-0.49)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Only father Aboriginal</td>
<td>0.96(0.73-1.26)</td>
<td>0.76</td>
</tr>
<tr>
<td>Only mother Aboriginal</td>
<td>0.68(0.48-0.95)</td>
<td>0.03</td>
</tr>
<tr>
<td>Mothers' age group in years at birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;20</td>
<td>1.51(1.28-1.78)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>20-24</td>
<td>1.48(1.33-1.66)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>25-29</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>30-34</td>
<td>0.89(0.79-1.00)</td>
<td>0.04</td>
</tr>
<tr>
<td>35-39</td>
<td>0.85(0.73-1.00)</td>
<td>0.57</td>
</tr>
<tr>
<td>≥40</td>
<td>0.78(0.52-1.16)</td>
<td>0.22</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3.69(3.33-4.09)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Socioeconomic disadvantage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Least disadvantaged</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Less disadvantaged</td>
<td>1.19(1.07-1.33)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Little disadvantaged</td>
<td>1.33(1.16-1.53)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>More disadvantaged</td>
<td>1.41(1.16-1.69)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Most disadvantaged</td>
<td>2.17(1.89-2.49)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

All parameters were included in the regression model so as to adjust each result for potential confounding by all other covariates.
Table 11. Hazard ratios and 95% confidence intervals of prescription stimulant medication in Aboriginal children and adolescents

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Univariate Analysis</th>
<th>Multivariate Analysis&lt;sup&gt;1&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HR (95% CI)</td>
<td>P-Value</td>
</tr>
<tr>
<td>Mothers' age group in years at birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;20</td>
<td>0.70(0.47-10.4)</td>
<td>0.08</td>
</tr>
<tr>
<td>20-24</td>
<td>1.10(0.80-1.50)</td>
<td>0.56</td>
</tr>
<tr>
<td>25-29</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>30-34</td>
<td>1.06(0.72-1.57)</td>
<td>0.78</td>
</tr>
<tr>
<td>35-39</td>
<td>0.98(0.54-1.77)</td>
<td>0.94</td>
</tr>
<tr>
<td>≥40</td>
<td>0.46(0.06-3.33)</td>
<td>0.44</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Male</td>
<td>4.51(3.27-6.23)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Geographical remoteness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Rural</td>
<td>0.83(0.61-1.13)</td>
<td>0.23</td>
</tr>
<tr>
<td>Remote</td>
<td>0.39(0.27-0.58)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Socioeconomic disadvantage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Least disadvantaged</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Less disadvantaged</td>
<td>1.05(0.68-1.63)</td>
<td>0.82</td>
</tr>
<tr>
<td>Little disadvantaged</td>
<td>1.25(0.78-1.99)</td>
<td>0.35</td>
</tr>
<tr>
<td>More disadvantaged</td>
<td>1.10(0.65-1.88)</td>
<td>0.71</td>
</tr>
<tr>
<td>Most disadvantaged</td>
<td>1.14(0.76-1.72)</td>
<td>0.53</td>
</tr>
</tbody>
</table>

<sup>1</sup>All parameters were included in the regression model so as to adjust each result for potential confounding by all other covariates.
6.5 DISCUSSION

Despite an increasing recognition of ADHD symptom among Aboriginal children and adolescents\textsuperscript{253,255,311} the risk of stimulant use for ADHD was markedly lower among individuals of Aboriginal parents than individuals of non-Aboriginal parents in our study. Parents are unlikely to pursue medication if they do not perceive ADHD as a clinical problem\textsuperscript{312}. Aboriginal parents who allow children freedom to explore their environment without restrictions to make them physically and emotionally resilient\textsuperscript{313}, may perceive hyperactivity and impulsivity as normal child behaviour.

Aboriginal children were subject to removal from their families historically through systematic policy of colonial intervention, but also to a lesser extent today through out-of-homecare programs\textsuperscript{314-315}. Parental separation and early attachment deprivation is a risk factor for ADHD in children\textsuperscript{316}. Aboriginal parents may attribute hyperactivity and impulsivity to child-removal-associated trauma which has been rooted in the Aboriginal cultural memory\textsuperscript{317}. This trauma has been advanced as a reason why treatment may appear to the Aboriginal parents as a repetition of the colonial practices\textsuperscript{43}, jeopardising abilities to fulfil their roles in family and community\textsuperscript{261}.

Stimulant use was notably lower in individuals of Aboriginal mothers than fathers, possibly due to the fact that Aboriginal women traditionally play a central role in family and community, and are solely responsible for caretaking and early child socialization\textsuperscript{263,318}. Conversely, another study reported fathers than mothers were associated with lower stimulant use in non-Anglophonic Australia communities\textsuperscript{287}. The authors argued that fathers who were less likely to perceive ADHD as a problem than mothers were the decision-maker about child health in non-English speaking communities.

We found lower risk of stimulant use among Aboriginals in non-metropolitan than in metropolitan areas likely due to geographical disparities in healthcare service access with shortages of health-related infrastructure in rural areas in Australia\textsuperscript{319}. Positive impact of community support and sense of belonging on protecting Aboriginal people against mental illness in both metropolitan and remote Aboriginal communities in Australia are documented\textsuperscript{320-321}. Yet, it is difficult to measure if the influence of the community support on mental health is greater in remote than in metropolitan
communities. In Canada, Currie et al. reported that while Aboriginal enculturation was protective against substance use and strengthened psychological wellbeing, mainstream acculturation weakens the influence of cultural ties and was a risk factor for substance abuse in urban Aboriginal adults. As Aboriginal people continue to urbanize in Australia, they may adopt beliefs and attitudes to ADHD medication of the mainstream urban society leading to the discrepancy in stimulant use between metropolitan and remote aboriginal communities here.

We made a number of other salient observations in this study. The first confirmed the well-known gender variation in stimulant use. Both Aboriginal and non-Aboriginal boys had elevated risk of stimulant use possibly due to the fact that boys commonly manifest hyperactivity and impulsivity which may closely entwine with heuristics and gender stereotypes influencing referral and diagnose. Secondly, the association between young maternal age and increased stimulant use risk is well established. A high level of maternal age and increased stimulant use risk is well established. An association however was not marked in Aboriginal groups hear, and may need further research. Thirdly, associations between socioeconomic hardship and increased stimulant use was in line with previous Australia studies. While a high prevalence of ADHD in marginalised children is well established, a large proportion of Australian children living in poverty were reported as being treated without meeting the ADHD diagnosis criteria. Hence, disadvantaged children who are more likely to be diagnosed with ADHD represent an important public health issue. Yet our finding of no association between disadvantage and stimulant use within Aboriginal groups is novel, however different interpretations exist and further investigation is warranted. One possibility is that within the Aboriginal population, social disadvantage correlates with ADHD symptoms and with a tendency not to receive treatment. Community support and cultural bond which have been shown to buffer mental and behavioural problems for marginalised people could be another explanation.

Some limitations need to be considered when interpreting our results. The datasets did not permit identification of individuals diagnosed with ADHD but not prescribed stimulants. It would have been useful to examine differences between diagnosis rate and stimulant treatment in Aboriginal children to investigate the likelihood of stimulant
over-or under-prescribing. In order to correctly identify Aboriginal people we triangulated information from two data sources; yet, it is still possible that Aboriginality is under-reported or misreported. It is also possible that our results were affected by unmeasured and, as yet, unidentified confounders.

6.6 CONCLUSION

Lower stimulant use for ADHD in children and adolescents of Aboriginal parents in our study suggests either Aboriginal parent perceive ADHD symptoms as normal child behaviour, have a negative attitude towards medication, or cultural competency provides a coping mechanism to make the ADHD symptoms functional. Alternatively, Aboriginal children who would stand to benefit from ADHD medication may face barriers to access. Aboriginal children should be protected from misdiagnosis and over-diagnosis; however, great care should be taken to ensure full access to appropriate services when required. A better understanding of Aboriginal perceptions of ADHD and stimulant treatment is crucial to identify vulnerabilities and develop targeted interventions and policy that account for social factors and align with Aboriginal culture to provide optimal care. We suggest two avenues for future research examining ADHD prevalence in Aboriginal children with narrowing of focus: first, for the rate of ADHD diagnosis and stimulant treatment to be investigated; and second, qualitative research to explore Aboriginal perception towards ADHD and stimulant treatment.
IDENTIFYING CROSS-CULTURAL VARIATIONS IN PSYCHOSTIMULANT USE FOR ATTENTION DEFICIT HYPERACTIVITY DISORDER USING LINKED DATA

This is an exact replication of the manuscript under review, albeit formatted for the thesis

7.1. ABSTRACT

Objective: To validate the association between country of birth and disparities in the prescription stimulant use for ADHD treatment in Western Australian children and young adults.

Methods: Using linked data, a population-based retrospective cohort of individuals admitted to hospital before age 25 years was followed through to identify having prescription stimulants for ADHD in 2003-2007. Multivariate logistic and linear regressions were used to characterise associations between prescription stimulants and country of birth, geographical remoteness and socioeconomic status.

Results: Of 679,645 individuals, 14,122 (2.1%) had a record of having prescription stimulants for ADHD treatment. Of these, 205 (1.5%) were born in Africa, Asia, Middle-East or South America, while 13,664 (96.8%) were born in Australia, New Zealand, Europe or North America. Individuals with traditionally non-Anglophonic backgrounds were around one-half as likely to have stimulants for ADHD treatment as individuals with Anglophonic backgrounds (OR=0.47, p<0.001). Non-Anglophones were an average of 2.7 years older than Anglophones at onset of having stimulants. Individuals from remote and disadvantage had stimulants for ADHD at younger ages than individuals living in metropolitan areas and with least disadvantage.

Conclusions: The results highlight the importance of identifying factors underlying cultural differences in stimulant treatment for ADHD, consistent with the hypothesis.
that stimulant use varies across cultures. Improving awareness of cultural variations may foster trust and rapport between patients and clinicians, and so better facilitate the appropriate and effective treatment of ADHD for each patient.

7.2. INTRODUCTION

Stimulants are the first-line modality of treatment for attention-deficit/hyperactivity disorder (ADHD), a commonly diagnosed chronic behavioural disorder in children and adolescents. Over the last decade the stimulant prescribing rate for ADHD in Australia rose 72% between 2000 and 2011\textsuperscript{24}, despite a significant community concern that ADHD is overdiagnosed and overtreated\textsuperscript{249}. It is surprising that we have limited information on cultural variations in prescription stimulant in Australia, and if cultural attitudes towards ADHD diagnosis and treatment influence medication use. In a previous study, Ghosh et al.\textsuperscript{287} reported about 83% lower stimulant uses among ethnic minorities in Western Australia and attributed the disparities to parental country of birth differences. We examined differences in prescription stimulant between children and young adults born in traditionally Anglophonic and non-Anglophonic nations, in order to validate the earlier findings, but in this instance using the countries of birth of the children. Using a similar methodology, we hypothesized that an individual’s country of birth would result in variation in stimulant use for ADHD. A more general context for our research is the value we place on promoting ecologically sensitive medical practice, when empirically justified.

7.3. METHODS

We conducted a population-based retrospective cohort study using the WA Data Linkage System and linked three statewide statutory health databases: the Hospital Morbidity Data Collection for inpatient separation, Monitoring of Drugs of Dependence System for stimulant records, and the Deaths Register\textsuperscript{270}. The linkage system is well-known for high sensitivity (95-99\%) and specificity (98-99\%)\textsuperscript{270}. The cohort included all individuals, ages 0-25 years, who were admitted into a hospital for any reason during 1980 to 2007, and followed through time to identify those who had a prescription stimulant between 2003 and 2007. WA is a state occupying the western third of the Australian continent with an estimated population of 2.5 million, around 11\% of the national total in 2013\textsuperscript{271}. It was impossible to use census data to obtain a precise
estimate of what proportion of the WA population aged 0-25 years were hospitalised at least once during 1980-2007. However, based on the relevant birth years of people resident in 2007, our approximate estimate was in the order of 40%. Individuals who died prior to 2003 were excluded from the study (Figure 13).

![Diagram of data collection and exclusion criteria]

Figure 13. Study design sample selection and exclusion criteria

### 7.3.1. Variables and measurements

Geographical remoteness was scored according to the Accessibility/Remoteness Index of Australia of the Australian Census, using whichever of the 1996, 2001 or 2006 indices were closest to the year of cohort entry, and was grouped into three levels: metropolitan, rural and remote\(^{286}\). The Index of Relative Socio-Economic Disadvantage from the Socio-Economic Indexes for Areas was used to categorise the study population into five levels of socioeconomic disadvantage ranging from most disadvantaged to least disadvantaged\(^{286}\).
Individuals’ countries of birth were grouped under eight major geographical regions of the world according to eHRAF databases – an internationally recognised anthropological databases facilitating study of human culture, society and behaviour. The eight groups were: Asia, Europe, Africa, North-America, Middle-East, Oceania (including Australia and New Zealand), Central-America and the Caribbean, and South America. The method used to classify country of birth are documented in detail in Ghosh et al paper where a pattern of reduced stimulant use was identified among individuals who were born in Africa, Asia, Middle-East or South America compared with those born in Australia/New Zealand, Europe or North America. As a result, we aggregated country of birth into Higher Propensity National Origin (HPNO), including Australia/New Zealand, Europe and North America, and Lower Propensity National Origin (LPNO) status for rest of the countries. For the purposes of the current study we focused our comparison on country of birth based on an individual’s HPNO and LPNO status.

7.3.2. Statistical analysis

The outcome measure was at least one prescription stimulant for ADHD dispensed during 2003-2007. Descriptive statistics were performed for all study variables, including means and standard deviations obtained for continuous variables, and frequencies and percentages for categorical variables. Univariate and multivariate logistic regression models were used to examine factors associated with stimulant use. Individuals’ age for initial prescription stimulants between 2003 and 2007 were compared using multiple linear regression. Missing values where information was unknown for each variable were treated as a separate ‘unknown’ exposure category so that all subjects were included in the analyses.

7.3.3. Ethics approval

The study was approved by the Human Research Ethics Committee of the University of WA and the WA Department of Health Human Research Ethics Committee.

7.4. RESULTS

Of the 679,645 individuals admitted to hospital for the first time by the age 25 years, 14,122 (2.1%) received a prescription stimulant for ADHD treatment during 2003-2007.
The characteristics of the cohort are shown in Table 1. Of individuals who received stimulants, the majority of them (n=13,664, 96.8%) were born in Australia/New Zealand, North America or Europe, with fewer (n=205, 1.5%) born in Africa, Asia, Middle-East or South America. Nearly 2% (n=253) did not have country of birth information. Individuals in rural and remote parts of WA comprised 17% (n=2401), compared with 70% (n=9869) who resided in the metropolitan area. Another 13% had missing residential information. Nearly one half (n=6650, 47%) came from the least socioeconomically disadvantaged group, whilst 7% (n=1002) belonged to the most disadvantaged group. There were 3.3 times more males receiving stimulant than females (76.7% vs. 23.3%).

Both univariate and multivariate models indicated that individuals with LPNO backgrounds were approximately half as likely to receive stimulants compared with those with HPNO backgrounds (OR 0.53, 95%CI 0.46–0.61, p<0.001) (Table 13). Females were 69% less likely to receive stimulants than males (OR 0.31, 95%CI 0.30–0.32, p<0.001). The odds of receiving a stimulant were significantly lower in those living in rural (OR 0.80, 95%CI 0.77-0.84) and remote areas (OR 0.43, 95%CI 0.38-0.48) than in the metropolitan areas. At univariate level the odds for having stimulants was 1.8 times greater (OR 1.08, 95%CI 1.01-1.15) in the least disadvantaged group than in the least disadvantaged, but the trend did not continue with greater levels of disadvantage. None of the examined disadvantaged group was a strong determinant of stimulant use after adjustment.

The mean age at onset of stimulant for those with a LPNO background was nearly three years older than in those with a HPNO background (14.98 vs. 12.27 years after adjustment, p<0.001) (Table 14). Males received stimulant at an average age of 12.78 years, about two years younger than females at 14.47 years. Individuals from rural and remote areas were also about one year younger than those from the metropolitan area. Similarly those from the least disadvantaged group were between 1.28 and 1.63 years older at the time of stimulant treatment compared with other socioeconomic groups.
Table 12. Characteristics of the study population according to stimulant medication use for ADHD

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>No stimulant used (%)</th>
<th>Stimulant used for ADHD (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants</td>
<td>66525</td>
<td>14122</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>340226 (51.1)</td>
<td>10834 (76.7)</td>
</tr>
<tr>
<td>Female</td>
<td>325295 (48.9)</td>
<td>3288 (23.3)</td>
</tr>
<tr>
<td>Unknown</td>
<td>2 (0.01)</td>
<td></td>
</tr>
<tr>
<td>Age at initial stimulant use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-4 years</td>
<td></td>
<td>108 (0.8%)</td>
</tr>
<tr>
<td>5-12</td>
<td>-</td>
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* HPNO (Higher Propensity National Origin) includes Australia/New Zealand, Europe and North America.
‡ LPNO (Lower Propensity National Origin) includes Africa, Asia, Middle East and South America.
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Table 14. Mean age in years in those receiving a stimulant medication for ADHD according to cultural and demographic factors

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<td>13.20</td>
<td>-1.63 (-1.96, -1.29)</td>
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† Reference Category
7.5. DISCUSSION

Our study found that prescription stimulants in WA varied significantly according to an individual’s country of birth. In particular, the odds of having stimulants in those born in Africa, Asia, Middle-East or South America were around one-half, and the mean age was 2.7 years older than in those born in Australia, Europe or North America. These findings are consistent with those documented in the earlier Ghosh et.al study, where a cohort of people born in WA between 1980 and 2007 was followed through time to identify those who had a stimulant record between 2003 and 2007 for ADHD treatment\textsuperscript{287}. That study employed a whole-population Australian birth cohort and used parental countries of birth as a proxy for ethnic groups, and so was not reliant on hospital admission for membership. The current study, on the other hand, had the advantage of including individuals born overseas, ascertained ethnic group using the individuals’ country of birth (not the parents). Our present results provide a validation of the earlier conclusions. The two different studies used cohorts constructed and measured in different ways, and were thus affected by different potential sources of error concerning external validity; yet the two studies have yielded similar results.

There were several limitations of the method used in this study. First, the individual’s country of birth variable was used as a surrogate given the absence of more direct ethnicity information. Groupings based on country of birth limited the capacity to detect differences between ethnicities and regional variations within countries to some extent, although it is generally agreed that country of birth plays a role in influencing individuals’ beliefs and attitudes. Second, detailed immigration information was unavailable and, therefore, we could not evaluate the association between stimulant use and refugee status or skilled migration. Third, our datasets did not allow us to identify anyone diagnosed with ADHD, yet not treated with stimulants. Fourth, as the stimulant data were only available from 2003, starting from initiation of the Stimulant Regulatory Scheme in WA, the first record in the stimulant dataset might not be the first stimulant record in individual’s life. Findings were further limited by the fact that records of dispensed prescription stimulant may not always determine the actual pattern of stimulant use for ADHD treatment, especially because there is a high prevalence of diversion and misuse of pharmaceutical stimulants among the adolescent and young adult student populations with ADHD\textsuperscript{328}. Nevertheless, our study contributes to
emerging evidence of the existence of ethnic differences in stimulant use, as we attempt to understand how ADHD behaviour is conceptualised in cross-cultural settings.

The strengths of this study compared with previous published studies were the use of whole-population linked data on a study population of nearly 700,000; a study cohort representing approximately 40% of the WA population aged 0-25 years between 1980-2007; and use of a comparison group of people with no records of stimulant use for ADHD. Whilst the representativeness of our cohort and the purity of exposure contract were far from perfect, they were superior to what can be achieved in a clinic-based research setting where subjects are typically highly selected and their treatments obtained outside unreliably recorded.

Cultural attitude towards ADHD behaviour and resistance to accept a biomedical cause of ADHD and medication treatment are the prime reasons for a reduced likelihood of prescription stimulant and delayed onset of stimulant use among LPNO groups. Individuals’ perceptions of normal and pathological behaviour are largely determined by cultural beliefs which influence their care-seeking behaviour. For example, ADHD behaviour was viewed by school teachers in India as childhood transition likely to improve as the child grew older. The researcher reported that the ADHD behaviour was perceived by the teachers as a positive trait of a child with higher physical energy levels and cognitive abilities. This cultural complexity in understanding ADHD behaviour in Indian society was reported to lead to a six-year gap between the noticing ADHD symptom and making a diagnosis. Similarly, culture-specific differences in attitudes towards symptoms of ADHD were reported in Iranian culture, where ADHD was viewed as signs of normal child development and independence leading to at least a two-year delay in treatment. Perceptual differences were also observed among Moroccan, Turkish and Surname immigrants in the Netherlands, with a higher treatment threshold for ADHD behaviour, resulting in a lower number of prescription medications in those immigrant children than in native Dutch children. Willingness to prefer medication treatment for ADHD behaviour is a pivotal cultural question that needs to be investigated.

Lower rates of medication treatment and delay in treatment were documented among Latino adolescents and youth in Venezuela largely due to a reluctance to accept
medication treatment94. Research suggested that cultural beliefs about the aetiology of ADHD influenced African-American and Latino communities to pursue alternative forms of treatment or decide not to pursue treatment at all65. Even when they accepted biomedical causes of ADHD, behavioural intervention was their preferred method of treatment than stimulant medication159.

Our findings also revealed that males were 69% more likely to receive stimulant than females possibly due to gender variation in ADHD manifestations, where boys exhibit more hyperactivity than girls, who display mostly inattentiveness331. As ADHD is considered a disorder of academic performance, excitability may cause disruption in a classroom situation, resulting in frequent diagnosis referrals and subsequent treatment in boys sometime even without valid cause324. While a high stimulant prevalence in boys is widely reported, a growing number of girls are being medicated for ADHD, leading to a declining male: female ratio in Australia211.

We found individuals living in the metropolitan areas were more likely to have prescription stimulants. Studies have examined differential healthcare access, availability of physicians and ready access to healthcare services in major cities as factors influencing regional variation in stimulant treatment332. Differences in beliefs and values about child behaviour and medical treatment, and the willingness to accept stimulant treatment may also vary geographically, contributing to a regional disparity333. The older age at commencement of stimulants in the metropolitan area than in rural areas in our results is a more difficult finding to explain. It may reflect a difference between metro and rural in the use of medication to improve academic outcomes, more so than to alleviate disruptive behaviours334 as those affected were aged more into their teenage years. A positive correlation between lower socioeconomic status and higher psychostimulant treatment has been documented previously in national and international studies228,305. Due to large socioeconomic discrepancies in stimulant use, some studies have uncovered concerns that psychosocial issues associated with socioeconomic disadvantage may be misattributed as symptoms of ADHD in children, leading to suggestions that medicalising behaviour, that might have been considered normal in the past, is a popular global phenomenon229,335.
7.6. CLINICAL SIGNIFICANCE

Our study contributes to the emerging literature emphasising the importance of ecologically sensitive clinical practices in relation to ADHD diagnosis and stimulant treatment. Lower prescription stimulant rates and a delay in treatment in non-Anglophonic groups, as well as geographical and socioeconomic variations in our study underline the need for greater awareness of socio-cultural complexities and better appreciations of the cultural norms and values that influence how ADHD is conceptualised and the challenges it may create for selecting appropriate interventions. As individuals cannot be separated from their cultural context, it is crucial to be aware of different cultural beliefs, values, attitudes and practices prior to developing any intervention program for ADHD. Developing awareness of cultural variations may improve the quality of the therapeutic relationship between patients and clinicians, and allow health providers to facilitate better treatment plans for behavioural issues.

7.7. CONCLUSION

Using a different method, this study validated cultural differences in stimulant treatment for ADHD reported in previous research, and identified significant country of birth variation, as well as gender, regional and socioeconomic disparities in stimulant use for ADHD in WA. Individuals born in Africa, Asia, Middle-East or South-America were less likely to have stimulant treatment than individuals born in Australia/New Zealand, Europe or North America. A greater likelihood of stimulant treatment among boys, individuals living in metropolitan areas, and living with socioeconomic disadvantage was also observed. The findings highlight the need for tailoring ADHD diagnosis, treatments and service delivery appropriately to children and adolescents from diverse cultures.
CHAPTER 8

LINKING PART A AND PART B: QUANTITATIVE AND QUALITATIVE RESEARCH PHASES

8.1 INTRODUCTION

This chapter serves as a link between thesis Part A the quantitative research phase and Part B the qualitative research phase, and explains how key quantitative findings informed the development of the qualitative phase of the thesis and the rationale for the qualitative research. The debate surrounding ADHD is emphasised to shed light on public opinion about ADHD and stimulant medication. Finally the scope of the study is outlined.

8.2 KEY FINDINGS OF PART A

While Chapters 5, 6 and 7 presented the findings of thesis Part A from the quantitative research phase in the form of manuscripts, it is crucial to synthesise the key insights from the quantitative studies that informed the design and focus of the subsequent qualitative research in thesis Part B. The key findings from the three manuscripts are summarised diagrammatically in Figure 14. Overall the quantitative studies highlighted that individuals of parents born in non-Anglophonic such as Africa, Asia, the Middle East and South American countries (referred to as LPNO in this thesis) were less likely to have stimulant medication for the treatment of ADHD compared with individuals of parents born in Anglophonic countries such as Australia/New Zealand, Europe and North America (referred to as HPNO) as reflected in Chapter 5. Similar to that, individuals who themselves were born in non-Anglophonic countries were less likely to use stimulants than their peers who were born in Anglophonic countries (shown in Chapter 7). The quantitative research also revealed that if stimulant treatment is administered, individuals or those whose parents were from LPNO background tended to delay onset of medication treatment later than in individuals with a HPNO background.
From the review of the literature, parents from LPNO backgrounds allegedly did not perceive ADHD as a pathological behaviour that requires medical interventions, but rather, they conceptualised ADHD behaviour as a natural phase of childhood development, which was expected to cease as the child grows up, thus they preferred non-medical intervention if intervention was needed\textsuperscript{55,165,296}. Parental fears of embarrassment and stigma associated with mental illness and psychiatric treatment were also reportedly observed in non-Anglophonic cultures, leading to delays in the onset of stimulant medication use for ADHD\textsuperscript{178,241}.

The quantitative studies also found variations in stimulant use according to gender, geographical remoteness and socioeconomic status. The findings suggested that the higher stimulant use in boys than girls are possibly due to heuristics and gender stereotypes, which may influence teachers’ decisions to refer more boys than girls\textsuperscript{48}, and clinicians’ decisions to diagnose more boys than girls even when criteria were not completely fulfilled\textsuperscript{324}. Geographical disparities in access to healthcare services with shortages of health professions and health-related infrastructure in rural and remote
areas in developed countries including Australia\textsuperscript{298,319} could be a possible explanation of lower stimulant use in rural and remote WA. Quantitative Study One reported in Chapter 5 highlighted a higher stimulant use in individuals with disadvantage, on the other hand, quantitative Study Two reported in Chapter 6 found no association between socioeconomic status and stimulant use.

While comparing stimulant medication use between the Australian born Aboriginal and non-Aboriginal population, the quantitative research in Chapter 6 showed that stimulant use was notably lower in individuals of Aboriginal parents than their non-Aboriginal counterparts. There is a paucity of research examining the prevalence of ADHD and stimulant use in Aboriginal populations. As well as reviewing the literature on Aboriginal perceptions of mental illness, the results in Chapter 6 suggested that Aboriginal people may not perceive ADHD as a clinical problem that can be addressed via medication treatment. The findings also suggested that other sociocultural factors and attitudes towards stimulant medication serve as a determinant of their access to ADHD health care services.

8.3 RATIONALE FOR THE QUALITATIVE RESEARCH

Throughout the literature, it was uncovered that people with LPNO backgrounds were unlikely to view ADHD symptoms as a medical condition, or as a problem that required medical intervention. Rather, they perceived those symptoms as natural child development that was expected to cease as the child grew up.

Thus, the quantitative findings evoked the questions: “why do individuals with HPNO background initiate stimulant medication”? “Is this only due to the understanding of ADHD as a medical condition or something else that is worth investigating?” While there are a handful of research studies examining the understanding of ADHD in non-Anglophonic peoples, there is a dearth of research of exploring Anglophonic people’s perceptions of ADHD and the reasons behind a preference for stimulant treatment. I wanted to investigate the personal, social and contextual factors that lay behind the decision to initiate stimulant medication for ADHD treatment. Thus the qualitative research explored how people from a ‘white, middle class background’ perceived ADHD like behaviour and how they conceptualised ADHD diagnosis and stimulant treatment. I use the term ‘white, middle class’ to denote my focus in the qualitative
research on people of Anglophonic/HPNO ethnicity with no particular impetus to seek out research participants who were either highly socially advantaged or highly socially disadvantaged. Australia is dominated demographically by a large middle class and it was within this main corpus of the population that my enquiries were focussed. Further, the participants’ ‘middle class background’ was decided based on their responses to the interview questions where they were asked to reflect on their experiences of the cost involved in ADHD diagnosis and treatment process. Thus the targeting of the qualitative research was consistent with the findings of the quantitative research.

8.4 QUALITATIVE RESEARCH

Using a qualitative method was the best way to get close to an answer to my question of ‘why’, whereas the quantitate studies were unable to proceed past the observations of ‘what’ differences existed. Through the qualitative study I was able to hear the voice of the individual taking ADHD medications directly, whereas I could not achieve this through the quantitative studies\(^{336-337}\).

According to Denzin and Lincoln\(^{338}\), in qualitative inquiry the observer is ‘located’ in the world that is being observed; and knowledge is likely to become ‘visible’ and ‘transformed’. As they explained:

“Qualitative research is a situated activity that locates the observer in the world. Qualitative research consists of a set of interpretive, material practices that make the world visible. These practices transform the world ...” (p. 3)

Strauss and Corbin\(^{339}\) believed that qualitative research produces findings “not arrived at by statistical procedures or other means of quantification” (p. 11). Patton\(^{340}\) emphasised that qualitative methods of research are well suited for exploratory studies in depth and detail and, rather than using specific hypothesis to be tested, they are suited to broader research questions. Patton further illustrated that “qualitative methods typically produce a wealth of detailed information about a much smaller number of people and cases” (p. 14) through observing, interviewing and analysing documents\(^{340}\). Creswell\(^{341}\) asserted that overall it is the “strive for understanding” (p. 243) that reinforces all qualitative research. The ‘strive for understanding’ encourages the researcher to re-examine data and to question the findings, which in turn may foster validity in qualitative research\(^{341}\).
Integrity, credibility, authenticity, criticality and trustworthiness are the essential criteria for all qualitative research\textsuperscript{342-343}. Tracy\textsuperscript{344} suggested a ‘big-tent’ of eight criteria to strengthen accuracy, consistency, reliability and overall quality in a qualitative research study. Tracy’s eight big-tent criteria are: 1) a worthy topic that is relevant and timely; 2) rich rigor through using appropriate theoretical constructs, sample, context, data collection and analysis processes; 3) sincerity and transparency of the methods and challenges; 4) credibility through thick description, concrete details, triangulation, and member reflections; 5) resonance that affects a variety of audiences through transferable findings; 6) significant contribution theoretically, practically, methodologically and heuristically; 7) ethical conduct in all procedures including situational and culturally specific ethics; and 8) meaningful coherence of the methods and procedures with study objectives and interconnected findings with the literature.

The qualitative phase of the thesis aligned with the above criteria. First, this was a relevant and timely study as outlined in the rationale in Chapter 1. Second, this study employed an appropriate method to explore individuals’ perceptions of ADHD through interviews as described in Chapter 9. Third, thematic analysis was selected for interpretation of the data (Chapter 9). Fourth, ethical and reflective practice was assured throughout all the procedures as outlined in Chapter 3. Fifth, research integrity and respectful relationships between the researcher and participants were recognised as reflected in Chapter 3. Sixth, authenticity and trustworthiness was confirmed through various perspectives, which were presented in text as thick description and concrete details. Seventh, the findings were interconnected with the literature in the field as described in Chapter 10, and triangulated with the quantitative results in Chapter 11. Eighth, a contribution to the body of knowledge that is practical and relevant for ADHD policy, practice and service delivery has been put forward.

### 8.5 GLOBALISING ADHD AND STIMULANT MEDICATIONS

As discussed in Chapter 2, two of the debates surrounding ADHD are whether ADHD is a distinct disorder and whether a diagnosis of ADHD should lead to pharmacological intervention, which may include methylphenidate, dexamphetamine or mixed amphetamine salt\textsuperscript{345}. The second debate is the particular focus of discussion due to the persistent rise in prescribing of these psychoactive medications in many parts of the
The rise in these stimulant prescriptions is mainly due to increased awareness of ADHD, as well as globalisation and medicalisation of signs and symptoms, which some argue have been considered normal in the past. The proliferations of ADHD and stimulant use have raised fresh concerns about the ethics of treating individuals with stimulants which have a potential for abuse. In 2001, a nationwide self-reported survey of more than 10,000 students in the USA reported a 6.9% lifetime prevalence of non-medical prescription stimulant use, including a past-year prevalence of 4.1%, particularly in white college students with lower academic grades. The majority of non-medical stimulant users in this survey reported obtaining the stimulants from a peer, who had a stimulant prescription for ADHD.

Revelations about non-medical use of methylphenidate, which has been described as the “smart pill”, by normal, healthy individuals for cognitive enhancement are a concern expressed in academic and scientific literatures. While reliable data on the prevalence of specific cognitive enhancement practices using prescription stimulant medications is not yet available, prevalence estimates of non-prescription stimulant use reported from the USA range from 5%–35%. Lakhan and Kirchgessner reviewed literature on prescription stimulants in individuals with and without ADHD, and reported that 25% of ADHD diagnosed college student with prescription stimulants misused their prescriptions to achieve high grades, and non-medically prescribed stimulant use was higher among dental, pharmacy and medical students to improve concentration and academic performance.

Objective data are lacking to confirm if ADHD medications actually do enhance academic performance or cognition; for example, Smith and Farah concluded that “…the cognitive effects of stimulants on normal healthy people cannot yet be characterized definitively…” (p. 717). Yet respondents have been reported to believe that the drugs are effective based on their own experiences. Students are also reported to feign ADHD in order to obtain a prescription for stimulant medication. In this regard, it is relevant that none of the currently used ADHD symptom checklists, neurocognitive tests or symptom validity tests have proven to be effective in separating feigners from those who have ADHD; adding fuel to the ongoing controversy in the public sphere about the proper identification of the condition.
In an Australia survey study, Partridge et al.\textsuperscript{353} reported that 2.4\% of the public without a diagnosis of ADHD had used a prescription stimulant to enhance their cognition, and a further 8\% were aware of someone who had done so. Partridge et al.\textsuperscript{354} then investigated the perceived motives for using drugs for cognitive enhancement by interviewing 19 university students. Unlike studies in US\textsuperscript{355} and Canada\textsuperscript{356}, where students believed that cognitive enhancement practices were common, the students in the Australian study were sceptical about the benefit of stimulants for cognitive enhancement and did not believe that the practice was common in Australia. Partridge et al.\textsuperscript{248-249} further reported a significant public concern about ADHD being over-diagnosed and stimulant medication being overused when individuals did not have the disorder, despite the fact that the rate of prescribing stimulants in Australian has been rapidly increasing over the last decade\textsuperscript{24}. Faced with these contradictory messages, it is crucial to know how individuals who are using stimulant treatment for ADHD, either for themselves or for their children, perceive ADHD and psychostimulant drugs, and how do they make a decision to commence drug treatments.

8.6 HOW DOES THE DECISION TO INITIATE STIMULANT TREATMENT OF ADHD ARISE?

Only a handful of qualitative studies have contributed insights into the meaning of ADHD and medication treatment for parents of children with ADHD from HPNO backgrounds. Interviewing parents of children with ADHD in London, Klasen and Goodman\textsuperscript{357} reported that the parents perceived ADHD as a long-lasting clinical problem, which required medical intervention. In their study, the diagnosis gave a relief from the burden of guilt for the parents who were worried that their doctors would blame them for their child’s problems. During interviews with American mothers\textsuperscript{220} and fathers\textsuperscript{155}, Singh focused on parental explanatory models for ADHD. In particular, mothers who experienced feelings of responsibility, inadequacy, shame, anger and guilt for their child’s ADHD condition adopted a medical framework for ADHD and positively accepted stimulant treatment. The fathers on the other hand, were sceptical of the medical model as providing an explanation of their child’s behaviour, and were resistant to medication treatment with stimulants.

Hansen and Hansen\textsuperscript{358} documented Canadian parents’ attitudes toward stimulant treatment as ‘dilemmas’ in which expectations about symptomatic and functional
improvements coexisted with concerns about medication safety and potential adverse effects. The parents in their study described their expectations regarding the medication’s role in their child’s future. Similarly, Coletti et al.\(^\text{359}\) in their study in New York documented multiple social, cognitive, and affective dimensions that influenced parental decisions to adhere to stimulant treatment. Parents who did pursue stimulant treatment maintained their sights on their child’s larger functional picture and future well-being.

Parents in an Australia study\(^\text{360}\) also shared their struggles with ambivalent feelings towards medication treatment, but reached a decision to medicate their child based on ‘doing right by my child’. Australian parents in another study\(^\text{361}\) revealed their experiences as difficult and confusing, fuelled by negative public perceptions of stimulant treatment; however, they highlighted the positive effects of medication in their child’s ADHD treatment.

### 8.7 SCOPE OF THE QUALITATIVE STUDY

I used the qualitative component of the study to understand in more depth how parents and individuals interpreted and made sense of ADHD behaviour and stimulant medication use for its treatment. My intention was not to explain or discover causes, not to judge the correctness of individuals’ opinions; but rather to clarify the meaning of phenomena from their everyday experiences with ADHD and stimulant medication. I applied a holistic approach focusing on the socio-cultural context to understand the perceptions of individuals with traditionally Anglophonic backgrounds about ADHD behaviour, diagnosis and stimulant treatment via the questions: how do people perceive ADHD behaviour, the meaning that the diagnosis carries for them and their attitudes to stimulant medication treatment. I interviewed eight participants who themselves or their children were diagnosed with ADHD and who were taking stimulant medications. The eight participants were sufficient in providing a rich insight into adult and parental perceptions through every day experiences with ADHD and its treatment.

I further wanted to explore perceptions of ADHD behaviour of people from traditionally non-Anglophonic backgrounds with an intention to find something which might not have been covered in previous findings. Having the two groups would also have enabled me to explore cultural differences in the expectation, diagnosis and treatment of
behaviours associated with ADHD. As such, I wanted to recruit participants from Asian, African, Middle-Eastern or South-American countries. I asked my participants if they knew any one from LPNO background with ADHD. I also posted a customised flyer to recruit participants with diverse cultural and linguistic background on the Health Point newsletter published by the DoHWA (Appendix VI) with no additional success.

“You would be lucky to get any of them” – one of my colleagues warned me. One Indian born mother expressed her interest to participate in this study, because she believed her son had ADHD. When I asked her if he was diagnosed or she was planning to get him diagnosed, she was somewhat offended and corrected herself by saying “oh no, no, it is not something I need to consult with a doctor. He will get over it – you know”! Her response resonated with findings from previous studies where Indian parents did not perceive ADHD as a medical problem176,242.

Recruiting Aboriginal participants in order to compare perception of ADHD and stimulant treatment between Aboriginal and non-Aboriginal Australians could have been appropriate. In particular, the quantitative study in Chapter 6 investigated the pattern of prescription stimulants for ADHD in Aboriginal individuals, and found noticeable differences in stimulant use between individuals of Aboriginal mothers and fathers. The qualitative study in the thesis could have been the ideal avenue to explore cultural complexities of Aboriginal communities through the looking glass of ADHD behaviour and attitude towards stimulant treatment. Obtaining an additional ethics approval from the WA Aboriginal Health Ethics Committee took seven months to analyse anonymous Aboriginal data from de-identified whole-population linked data which had already been approved by the DoHWA Human Research Ethics Committee. Given the limited time of my doctoral candidature, I found it impractical to wait for any longer to obtain another ethics approval to recruit Aboriginal participants for interviews.

### 8.8 CHAPTER SUMMARY

This chapter contained a description of the manner in which thesis Part A the quantitative research phase and Part B the qualitative research phase were connected, through summarising the key findings of the quantitative phase that guided and determined, along with the current literature on the use of stimulant medication for
ADHD and the scope of the qualitative study. In the subsequent chapter the qualitative research method including theoretical approach, participant recruitment, data collection and data analysis are presented.
CHAPTER 9

QUALITATIVE METHODOLOGY

9.1. INTRODUCTION

This chapter describes fieldwork methods used in the qualitative phase. The qualitative study was built on the findings of the two quantitative studies in Part A as described in the previous Chapter 8. In this chapter, I present the philosophy underpinning this qualitative methodology. The philosophical stance was considered throughout participant recruitment, data collection process and data analysis which are described in detailed. The findings are presented as a manuscript in Chapter 10.

9.2. RESEARCH QUESTIONS

The study set out to understand individual’s perception of ADHD. The following questions were considered:

- How do people perceive ADHD behaviour?
- What does ADHD diagnosis mean to them?
- How do they feel about stimulant medication treatment?

9.3. THEORETICAL APPROACH

The qualitative approach utilised for this study was underpinned by a social constructivist philosophical stance which emphasizes the way individuals seek to understand their world and construct their own particular meanings that correspond to their experience\(^\text{341}\). Constructivism assumes that knowledge and truths are created by the individuals’ everyday interactions\(^\text{362}\). This paradigm is inductive and values the unique experiences, perspectives and truths of individuals\(^\text{340}\). As Lincoln et al.\(^\text{343}\) describe constructivism as a worldview acknowledges that knowledge is generated and gathered through “individual and collective reconstructions” that build “more informed and sophisticated reconstructions” (p. 101).
In a qualitative inquiry, “the nature of reality and its characteristics” are understood from different perspectives, which Lincoln et al. described as the ‘relativist ontological’ stance that constructivism follows. A constructivist worldview is also described as having a ‘subjective epistemological’ stance which suggests multiple understandings of the world, and multiple experiences of reality are possible, and these understandings and experiences are often defined and redefined through everyday interactions with others. Hence, in a qualitative enquiry it is suggested that data need to be presented in a way that mirrors the different understandings and multiple experiences of reality of the participants. Lincoln et al. emphasised the ‘trustworthiness’ and ‘authenticity’ of the data collection and interpretation of data as prime criteria that align with a constructivist worldview. At the same time, it is also recommended that qualitative data are to be interpreted and presented with an empathic stance and without judgement.

9.4. SAMPLING

9.4.1. Sample size

As mentioned, this study was conducted from the constructivist standpoint to gain a deeper understanding of individuals’ perceptions through experiences. Therefore, I did not attempt to design a study from which the results of a representative sample could be generalized to a larger population. Further, the sample size in qualitative research is determined by the purpose of the inquiry, usefulness, time and resources. In a qualitative study using open-ended in-depth interview approaches engaging a small number of participants, such as 4 to 10, are common to elicit patterns and relationships of particular meanings that correspond to the experiences described by the participants. To find out how many interviews were needed to get a reliable sense of thematic exhaustion and variability, Guest et al. found that the basic elements for metathemes occurred as early as six interviews. I kept in mind that my study group sample was to be broadly representative of the study population and I remained faithful to the concept of saturation – when the collection of new data no longer provided any further information on the research inquiry. While sufficiency and saturation were useful for sample size determination and data collection, I also took into account the practical exigencies of time and resources allocated to my doctoral study where I used...
both quantitative and qualitative research methods\textsuperscript{365-366}. Consequently, I made use of a sample of eight information-rich participants who volunteered to engage with the study.

9.4.2. Recruiting participants

Finding adults as well as parents of children diagnosed with ADHD willing to participate in my study was challenging. Given that ADHD is a sensitive issue, to get in touch with potential participants I employed a gatekeeper approach, reliant on school principals, clinicians and members of ADHD support groups. I contacted seven primary school principals, introducing myself, explaining my role as a researcher and providing them with an overview of the study. Only one of the school principals responded to me by placing a notice on his school newsletter. I obtained permission to attend ADHD self-support groups facilitated by Learning and Attentional Disorders Society of WA (LADSWA), outlining my research, participant information and consent form (Appendix VII & VIII). Three clinicians, including psychiatrists and paediatricians, in the Perth metropolitan area were also contacted. Expressions of interest were at first disappointingly low, so I used a snowball technique\textsuperscript{367}, through which I contacted participants via networks that I had gradually created. The parameters for selection of participants were: parents (either father or mother) or guardians of children aged 2 to 17 years diagnosed with ADHD, and adults aged 18 or more years diagnosed with ADHD, able to converse fluently in English, and living in Perth. One of the eight interviews was, however, conducted with a mother of children aged 20-23 years and diagnosed with ADHD. This mother felt she could share many years of her experience of parenting children with ADHD including during my target age range, and on this basis I included her experiences in the study. Two more mothers with ADHD children expressed their interest in participating in this study. However, I did not recruit them as no further new information was anticipated due to their similar sociocultural background to the rest of the participants.

9.4.3. Participants

The sample comprised one man and seven women aged from 30 to 60 years. All were Caucasians with five born in Australia, and three born in the US, UK and South Africa (Table 16). Of those born overseas, two had been living in Australia for 22-26 years, and one migrated five years ago prior to starting a family. All were English speaking
and resided in the Perth metropolitan areas. They all had university degrees, five were professionals, two were stay-home parents and one was a student. Having a homogenous sample of participants was helpful to provide rich qualitative information with distinctive characteristics for this study with a small sample. Six of the participants were parents of children (aged 3-23 years) who were receiving stimulant treatment for ADHD; one grandmother of an ADHD adolescent; and one adult diagnosed with ADHD and depression and had no children. Three parents were also diagnosed with ADHD at age 40-45 years, and another two were diagnosed with depression.

<table>
<thead>
<tr>
<th>Demographic factors</th>
<th>Variants</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
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<td></td>
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</tr>
<tr>
<td>Age group in years</td>
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<tr>
<td></td>
<td>41-60</td>
<td>6</td>
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<td>Caucasian</td>
<td>8</td>
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<tr>
<td>Country of birth</td>
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<td></td>
<td>Post graduate</td>
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<tr>
<td>Diagnosed with</td>
<td>ADHD</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>3</td>
</tr>
<tr>
<td>Relationship</td>
<td>Mother</td>
<td>5</td>
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<tr>
<td></td>
<td>Father</td>
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</tr>
<tr>
<td></td>
<td>Grandmother</td>
<td>1</td>
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<td></td>
<td>Adult with no children</td>
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</tr>
<tr>
<td>Had child/ren with ADHD</td>
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<td>3</td>
</tr>
<tr>
<td></td>
<td>More than one child</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Had no children</td>
<td>1</td>
</tr>
</tbody>
</table>
9.5. DATA COLLECTION

The primary method used in the study was face-to-face, semi-structured interviews with a protocol of open-ended questions (Appendix IX) in line with a social constructivist paradigm. The reasons I opted to use semi-structured interviews with open-ended questions for data collection were threefold. First, the face-to-face interviews allowed me to explore the participants’ personal views and experiences, which I could not observe directly\(^{340}\). The interview captured their ideas and thoughts in their own words, enhancing rigor in the course of conducting this study\(^{368}\). Second, the semi-structured interview enabled me to keep the discussion of relevant topics on track within a limited time, while providing the freedom for immediate clarification or expansion of the participants’ thoughts, and for following up on specific matters that arose during the interview\(^{369}\). Third, the open-ended interview facilitated the collection of rich and detailed aspects of the participants’ experiences, because

“... open-ended responses permit one to understand the world as seen by the respondents. The purpose of gathering responses to open-ended questions is to enable the researcher to understand and capture the points of view of other people without predetermining those points of view through prior selection of questionnaire categories”\(^{340}\) (p. 21).

Background demographic information was initially collected through a brief questionnaire that took no longer than five minutes to complete (Appendix X). Issues explored during the interview sessions included influences of culture, education, knowledge and personal beliefs and socio-economic status on the decisions to accept an ADHD diagnosis and to take medication for ADHD, and the inter-relationships between the two. Arrangements for the interviews were made so as to accommodate the participants’ preferences on the interview location, thus allowing them to exercise shared control over the interview situation. This made the interview session non-threatening, relaxed, comfortable and convenient from their perspectives\(^{370}\). Three participants opted to be interviewed in my university office, two invited me to their home, two chose their work offices and another one wanted to have an outdoor interview in a park. Each interview lasted approximately an hour – long enough to encourage them to talk freely, but not too long to tire them.
It was important to record as completely as possible each participant’s viewpoint without any interpretation, because

“direct quotations are a basic source of raw data in qualitative inquiry, revealing respondents’ depth of emotion, the ways they have organized their world, their thoughts about what is happening, their experiences and their basic perceptions”³⁴⁰ (p. 21).

With participant’s’ permission all interviews were thus recorded on a digital voice recorder. I explained that I did not want to miss anything they said or inadvertently change their words while making notes. I informed them that they could turn the voice recorder off at any time during the interview. Recording the interviews did not appear to be an issue. Apart from the increasing the accuracy of the raw information, the voice recorder allowed me to listen more attentively and respond appropriately to the participant cues³⁴⁰. The recording also allowed the situation to retain a more conversational feel compared with copious note taking.

9.5.1 Enhancing rigor through interview

Each interview began with a brief explanation of how the session would proceed and with reassurance that they could pass over any question they did not want to talk about and could withdraw altogether at any time. The interview then proceeded using the semi-structured questions as a guide. To keep all interviews consistent and transparent, I asked each participant the same questions, although I had to change the order of the questions and ask additional questions depending on the nature of the discussion. Throughout the interviews, I wanted my participants to provide in-depth information pertaining to their experiences, attitudes and viewpoints on ADHD behaviour, while also providing factual information³⁷¹. I wanted to enter into their perspective, and to listen to their life stories influenced by the cultural context to which where they belonged³⁷². Therefore, I conducted one-sided talk, but intervened occasionally with the use of paraphrasing to feedback what I heard to the participants, and to clarify their experiences and perspectives. I also used probing questions to bring the participants back to the topic, if they wandered too far off it. Probing questions were used also when necessary to ensure coverage of all major themes pertaining to the aims of the study³⁷². When the participants were apparently finished on a point, I asked follow-up questions to allow them to elaborate on their responses and to shed light on their further
thoughts. This was achieved by taking note of comments or phrases that they had used while talking, which enabled me to refer them back to a key point later in the interview\textsuperscript{369}.

In the course of interviews, I encouraged my participants to describe and reflect upon what their experiences had been like for them. I explored their personal emotional reactions by asking such questions as “How do you feel about [your child] having ADHD?”, “What do you think about it?”, “What do you do about it?”, “Why do you do this?” Such interviews “produce[d] rich material bearing on feelings and understandings about feelings and their transformations throughout various stages of life”\textsuperscript{373} (p. 224). I applied this method to ensure that I found out what each participant had to say about their lives as experienced and, in particular, their perceptions of ADHD.

I ensured empathy in this study throughout data collection. Conducting one-sided talk I provided the participants comfort with silences, while paraphrasing emphasised active listening for ‘responsive interviewing’\textsuperscript{374}. The follow-up questions allowed me to acknowledge and reflect of their experiences without confronting or challenging their views, and as such enabled me to build rapport and trust between myself as the researcher and the participants.

### 9.5.2 Data elements and measurement

In order to address the research questions in this study, diverse data elements were used to measure different factors and variables. The following key factors in Table 16 were used to measure the variables in this research.
Table 16. Key data elements and measurement

| 1. Conceptualising and understanding of ADHD behaviour | a) What behaviour do they find abnormal?  
b) At what age was the ADHD behaviour observed?  
c) How has the behaviour changed since then?  
d) What was the feeling about the behaviour? |
|---------------------------------------------------------|----------------------------------------------------------------------------------|
| 2. Causes of ADHD behaviour | e) How do they view ADHD behaviour?  
f) What do they think about the cause of ADHD behaviour?  
g) Who do they think is responsible for this condition?  
h) What prior knowledge did they have about ADHD? |
| 3. Seeking psychostimulant treatment | i) How was the decision made to see a professional?  
j) What was the procedure to see a professional?  
k) What treatment option was considered and why?  
l) What was the experience with the professional?  
m) The feeling after being given the ADHD diagnosis |
| 4. Experience with the psychostimulant treatment | n) What was the feeling of being prescribed medication?  
o) What was the experience after taking the medication?  
p) The differences observed in behaviour before and after medication?  
q) Any experiences with non-medication treatment? |
| 5. Social value and expectations | r) How was their life compared to their friends’ life?  
s) How do they perceive what other people think about them?  
t) How do they want other people to see them? |
| 6. Family and social support | u) What supports are received from family and friends?  
v) What social supports are received?  
w) How were the support appreciated? |

9.6. DATA ANALYSIS

Audio recordings of all interviews were transcribed verbatim by myself, and a thematic analysis of the transcriptions was conducted. Thematic analysis is a qualitative data analytic “method for identifying, analysing and reporting patterns (themes) within data. It minimally organizes and describes … data set in (rich) detail. However, frequently it goes further than this, and interprets various aspects of the research topic”\(^{375}\) (p.79). Thematic analysis is appropriate for exploring and understanding individuals’ experiences which are often multi-dimensional and multi-layered whilst elucidating various aspects of the research topic.

Braun and Clarke’s\(^{375}\) guide to six phases (Figure 14) of conducting thematic analysis: familiarising with data, generating initial codes, searching for themes, reviewing themes, defining and naming the themes, and report producing. These phases were not seen as operating independently, but rather overlapped with each other.
At the first phase of data analysis, I listened to the interview tapes and read and re-read the transcripts of interviews, giving due attention to every bit of information to immerse myself in the transcripts in order to become familiar with data and to obtain a holistic perspective of the participants’ experiences. I highlighted sections of the transcripts and produced rough notes, which were called memos, to reflect my initial observations, an important element of data analysis to enable the comparison and contrast of individual interviews.

The second phase of analysis involved extracting and coding significant statements or moments of experience pertaining to the participants’ conceptualisations of ADHD, diagnosis and treatment. Next, codes were collated into potential themes which captured “something important about the data in relation to the research question and represent[ed] some level of patterned response or meaning within the data set” (p. 82). At this phase all themes were grouped to develop overarching themes and sub-themes. In the fourth phase, all overarching themes and sub-themes were then re-checked in relation to the coded data extracts as well as to the entire transcriptions and refined for an authentic reflection of the participants’ experiences. This phase necessitated a more focused analytical ordering of themes and subthemes.

The fifth phase involved generating definitions and names for each theme to tell the overall story. At this stage the participants’ own words were arranged and linked to each theme to form a first-person narrative. The final phase of the data analysis consisted of a selection of vivid and compelling extract examples, relating the analysis back to the research question and literature.
9.7. CHAPTER SUMMARY

This chapter contained qualitative methodology including theoretical principles of the qualitative research. The qualitative method which included interviews was described in detail, and description of participant recruitment and data collection followed. The thematic data analysis of the interviews was illustrated. The following chapter presents the qualitative findings as a manuscript.
“IT HAS TO BE FIXED”: A QUALITATIVE INQUIRY INTO
PERCEIVED ADHD BEHAVIOUR AMONG AFFECTED
INDIVIDUALS AND PARENTS IN WESTERN AUSTRALIA

This is an exact replication of the journal publication, albeit formatted for the thesis

10.1. ABSTRACT

Background: The use of stimulant medication for Attention Deficit Hyperactivity Disorder (ADHD) to improve classroom behaviour and sustained concentration is well known. Achieving a better academic grade has been reported as the prime motivation for stimulant use and is an increasingly discussed topic. The proliferation of stimulant use for ADHD has been a cause for public, medical and policy concern in Australia. This paper explores individuals’ perceptions of ADHD, the meaning that the diagnosis carries for them and their attitudes to stimulant medication treatment.

Methods: This qualitative study was underpinned by a social constructivist approach and involved semi-structured interviews with eight participants. The participants were parents of children with ADHD or were adults who themselves had been diagnosed with ADHD. Interviews were audiotaped, transcribed verbatim and thematically analysed.

Results: There were three interrelated yet contradictory groups of themes: (i) An impairment to achieving success, which can be a double-edged sword, but has to be fixed; (ii) Diagnosis as a relief that alleviates fault and acknowledges familial inheritance; (iii) Responsibility to be normal and to fit in with societal expectations. Collectively, these perceptions and meanings were powerful drivers of stimulant use.

Conclusion: Paying attention to perceptions of ADHD and reasons for seeking or not seeking stimulant treatment is important when planning appropriate interventions for this condition.
10.2. BACKGROUND

Attention Deficit Hyperactivity Disorder (ADHD) is defined as a chronic neuro-developmental disorder characterised by the core symptoms of hyperactivity, impulsivity and inattention\textsuperscript{2}. It affects more than 7% of children\textsuperscript{90} with a higher prevalence among boys\textsuperscript{324}. There has, however, been considerable argument surrounding the aetiology of ADHD, questioning whether it is a neuro-genetic condition or a socially constructed illness\textsuperscript{14}. The debate is fuelled in part by the general if not ambiguous nature of ADHD symptoms defined in the DSM-V\textsuperscript{2}. Some argue that children often display behavioural characteristics that include features analogous to the symptoms of ADHD, such as hyperactivity and inattentiveness\textsuperscript{121}. Additionally, the treatment of ADHD with psychostimulant medication has been controversial and the focus of much debate in developed countries including Australia, due to the subjectivity of the diagnosis as well as the ethics of treating children long-term with substances that have the potential for abuse\textsuperscript{33,335}. Much attention has also been paid to the short and long-term effects of stimulant use including the risk of cardiovascular complications\textsuperscript{39}.

Prescriptions for stimulant medication have risen sharply in Western countries over the last decade\textsuperscript{203-205}. In Australia, the rate of stimulant treatment rose 72\% between 2000 and 2011\textsuperscript{24}, representing an average annual growth of 4.7\% and exceeding estimated growth rates in the US by 1-2\%\textsuperscript{21}. The persistent rise reflects widening diagnostic criteria\textsuperscript{88}, an increase in studies purporting benefits from early recognition of ADHD and the efficacy of stimulant medications\textsuperscript{30}, effective marketing by pharmaceutical companies and a greater acceptance of stimulant treatment among health professionals\textsuperscript{376}. This proliferation of stimulant treatment has been cause for public concern that too many children are diagnosed with ADHD and treated with stimulant medications when they do not actually have a disorder\textsuperscript{249}. The stimulant medications that are recommended by American Academy of Paediatrics\textsuperscript{183} may lessen the severity of ADHD symptoms, increase attention and concentration, and improve classroom behaviour\textsuperscript{19}. However, it has been noted that short-term stimulant treatment showing improvement in childhood does not necessarily have lasting effects into the adolescent years\textsuperscript{201}. Further, the medications do not promote learning or improve cognitive ability\textsuperscript{377}. Nevertheless, it has been reported that they are used for the purpose of neurocognitive enhancement\textsuperscript{335}. Parents are more likely to adhere to stimulant treatment if their child has a cognitive impairment\textsuperscript{378}. Achieving better academic grades
and enhancing cognitive performance is reported to have been the prime motivation for stimulant use among asymptomatic students, who feigned the features of ADHD in order to obtain prescriptions. In light of polarised debate, yet increasing use of stimulant treatment, individuals’ perceptions and experiences related to their child’s or their own diagnosis and treatment are important, but have largely been ignored. Taylor et al. suggested that parents’ decisions to administer psychostimulant treatment are based on their own blend of personal experience, observations of societal norms and media reports. Understanding individuals’ perceptions of and attitudes towards stimulant treatment is important for appropriate intervention and proper management. Understanding which members of the community are more willing to accept stimulant treatment and the factors that make stimulant use more acceptable would be helpful to avoid over-diagnosis and overtreatment.

This study used a qualitative approach to understand how parents of children diagnosed with ADHD, as well as adults diagnosed with ADHD perceived ADHD behaviour and stimulant treatment. The objectives of this study were to explore individuals’ perceptions of ADHD behaviour, the meaning that the diagnosis carries for them, and their attitudes to stimulant treatment derived from their everyday experiences.

10.3. METHODS

The qualitative approach used for this research was underpinned by a social constructivist philosophical stance, which emphasized the way individuals seek to understand their world and construct their own particular meanings that correspond to their experiences. It assumes that knowledge and truths are created by the individual’s everyday interactions. Constructivism therefore assisted in the understanding of how the participants in this study perceived ADHD behaviour and stimulant treatment.

10.3.1. Sample

Participants were recruited through volunteer sampling. An information sheet was distributed to primary schools, Department of Health Western Australia (WA) facilities,
and the Learning and Attentional Disorder Society Support Groups in WA. A snowball technique, in which participants were contacted via networks, was also employed\textsuperscript{367}. Participants were selected based on the following criteria\textsuperscript{340}: those who themselves were diagnosed or had dependent children diagnosed with ADHD; aged over 18 years; and were able to converse fluently in English. We received expressions of interest to participate in this study from ten people with similar ethnic and socioeconomic backgrounds. Data saturation was reached after collecting information from eight participants as no further new themes emerged from the analysis\textsuperscript{365}. The participants were aged 30-60 years, seven of them were female, and all were English speaking and resided in the Perth metropolitan area (see Table 17).

Table 17. Demographic characteristics of the study participants.

<table>
<thead>
<tr>
<th>Total participants (n= 8)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
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<tr>
<td>Male</td>
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<tr>
<td><strong>Age group in years</strong></td>
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<tr>
<td>20-40</td>
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<tr>
<td>Depression</td>
</tr>
<tr>
<td><strong>Had child/ren with ADHD</strong></td>
</tr>
<tr>
<td>One child</td>
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<tr>
<td>Had no children</td>
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<tr>
<td>Mother</td>
</tr>
<tr>
<td>Father</td>
</tr>
<tr>
<td>Grandmother</td>
</tr>
<tr>
<td>Adult with no children</td>
</tr>
</tbody>
</table>
The sample comprised six parents of children with ADHD (aged 3-23 years), one grandmother of an ADHD child aged 17 years and one childless adult diagnosed with ADHD and depression. Four parents had more than one child diagnosed with ADHD. Three parents were also diagnosed with ADHD at ages 40-45 years and another two were diagnosed with depression. All participants described their race as Caucasian with five born in Australia and three born in the US, UK and South Africa respectively. Of those born overseas, two had been living in Australia for 22-26 years and the third immigrated five years ago prior to starting a family. They all had university degrees, five were professionals, two were stay-home parents and one was a student.

10.3.2. Data collection procedure

In order to understand the individuals’ perceptions towards ADHD behaviour, after obtaining signed consent to participate, semi-structured face-to-face in-depth interviews were conducted to capture participant beliefs and thoughts in their own words. Seven key questions guided the interview sessions were:

1. How was the decision made to seek for professional help?
2. How did you feel being/your child being diagnosed with ADHD?
3. Who do you think is responsible for this condition (ADHD)? Why
4. How was the decision made to administer medication?
5. How do you feel about administering medication for ADHD?
6. How was your/child’s behaviour and your decision to administer medication received by your family and friends?
7. How did their response make you feel? How did you want them to make you feel?

The semi-structured interview kept the discussion on track within the available time restraints. Each interview lasted approximately one hour. This was long enough to encourage participants to talk freely, but not too long to tire them. To keep all interviews consistently focused yet uninhibited, each participant was asked the same questions, but with a change in the order of questions as appropriate to maintain the flow of the interview. Additional open ended questions were used as prompts, depending on the nature of the discussion. With each participant’s permission all interviews were audio-recorded. The interviews took place at participants’ homes or at other alternative participant-nominated locations to allow them to retain some control.
over the interview situation and to render the interview session non-threatening, comfortable and convenient for them\(^{370}\).

**10.3.3. Data Analysis**

Thematic analysis of participants’ transcribed interviews was conducted. Thematic analysis is a qualitative analytic “method for identifying, analysing and reporting patterns (themes) within data”\(^{375}\) (p. 79). Thematic analysis is appropriate for exploring and understanding individuals’ experiences, which are often multi-dimensional and multi-layered, whilst elucidating various aspects of the research topic. Braun and Clarke’s\(^{375}\) have defined six phases of conducting thematic analysis: familiarising with the data; generating initial codes; searching for themes; reviewing themes; defining and naming the themes; and report producing. Audio recordings of all interviews were transcribed verbatim and the transcriptions were carefully read several times to become familiar with the data to obtain a holistic appreciation of participants’ experiences. Salient words, phrases and sentences used by the participants were highlighted in this phase. Participants’ statements or moments of experience were then initially coded so as to capture their ideas. Next codes were collated into potential overarching themes and sub-themes. In the fourth phase, all overarching themes and sub-themes were then re-checked against the coded data extracts, as well as the entire original transcriptions and refined to ensure an authentic reflection of the participants’ experiences. This phase necessitated a more focused analytical ordering themes and subthemes. The next phase involved generating definitions and names for each theme to tell the overall story. The final phase of the data analysis consisted of selection of vivid and compelling extract examples, relating the analysis back to the research question and literature. The first author carried out the data collection and data analysis and other co-authors contributed to study design, formulation of data analysis plan and interpretation of findings.

**10.3.4. Rigour**

An in-depth face-to-face interview method was used to explore individuals’ perceptions and beliefs towards ADHD and stimulant medication use in their own words. Therefore, the research method was anchored in the constructivist tradition to construct knowledge, meaning and understanding through human interactions, and so the trustworthiness was ensured in the course of conducting this study\(^{380}\). Rigour was also
enhanced through familiarity with and continual immersion in the data at every step before and during analysis\textsuperscript{375}. The validity of individual overarching themes and sub-themes in relation to the data set was ensured through continual revision and checking of coded data extracts and transcriptions, individually and collectively, to reflect accurately the meanings evident in the data as a whole\textsuperscript{375}. Producing the research findings to tell the complex story of the participants’ perceptions and experiences was another way to ensure the validity of the analysis\textsuperscript{375}.

10.3.5. Ethics approval

The study adhered to ethical principles according to the NHMRC guidelines for conducting human research\textsuperscript{269}. Ethical clearance was obtained from The University of Western Australia Human Research Ethics Committee. As part of this approval, each participant received a written participant information sheet, advising that participation was voluntary and assuring the person that they could decline to answer any question that they felt uncomfortable with and that they were at liberty to withdraw at any time without consequence. The anonymity of the participants was protected by using pseudonyms.

10.4. RESULTS

The analysis of the interviews revealed three overarching themes with two sub-themes for each. In sharing their experiences, participants touched on many common themes, yet sometimes these were in direct contradiction to one another, demonstrating the complexity of the topic. Collectively, the interrelated yet contradictory perceptions and meanings were powerful drivers of stimulant use and are illustrated in Figure 16.

10.4.1. An impairment to achieving success

10.4.1.1. It’s a double-edged sword

In discussing their experiences the participants expressed their negative and positive views towards ADHD. Parents reflecting on their experiences of their children suggested that children with ADHD were ‘difficult to manage’, ‘challenging’, ‘exhausting’, ‘not normal’ and had something ‘wrong’ in them. The parents stated that ADHD had a profound impact on their children’s learning at school, and noticed ‘lack of concentration’, ‘struggling with school work’, ‘not achieving at school’ and having
‘no friends’. Some noticed an emotional roller coaster in their children and one felt that her son was suicidal.

_I didn’t realise that the emotional problem that [my son] was experiencing was direct result of ADHD. I knew his hyperactivity was, but I didn’t know the emotional difficulties he had. I didn’t understand the impact of ADHD he had. I just saw the hyperactivity thing ... struggling at school ... but by the time he was 15, things were coming apart and really I did worry that he would suicide._ (Jo)

As adults, participants described similar experiences including ‘lack of concentration’, ‘unable to remain seated’, difficulties in ‘waking up in the morning’, ‘organising tasks’, and ‘working with co-workers’.

Despite the difficulties they experienced, as parents, the participants often added positive attribution of their child’s ADHD for higher physical energy levels and cognitive abilities. Some believed that people with ADHD could be highly intelligent, and articulated that ADHD symptoms could be seen among famous people like ‘Aristotle’ and ‘Einstein’ throughout history. Annette had two of her children diagnosed with ADHD, and she thought:

_First it was a curse. It was so hard to control; it pulls them so difficult, they torn of their different feelings [sic]. But other side some of the things they do are amazing. It is like a gift, having extra especial power, but whether you can control them?_

Jo perceived a positive side of ADHD along with its negative connotation. She found her ADHD child was fun:

_He was intellectually challenging and fun to rear ... interesting ... creative so far out of the box ... you have to have eyes [in the] back of your head ... never a dull moment ... exhausting and emotionally scarring but incredibly interesting ... intellectual stimulus ... you can put [it] that way._

Jo was also diagnosed with ADHD and taking medications. She compared her life to her friends’ lives, and described:

_They [her friends’ lives] are organized and dull – my one is chaotic and fun. We see more funny connection than other people see – more interesting ... one of my friends said I was lot more fun before [treated]._
She then added when she was asked about her perception towards ADHD:

*I think about this a lot and I’m not sure. We read a lot about those outstanding individuals for whom ADHD has been a blessing that they have made great discoveries and they are enormously successful .... There was a belief that human clan would not succeed without ADHD people in the society ... [but] the flip side of me says, the success stories that ... you do not hear about people who had their life in hell because of the emotional difficulties that ADHD creates. My son and I talked about this a lot. We both agreed [that]… the technicolour as we call the life we live is not worth, we prefer the black & white that everybody lives. So ... it’s a double edged sword ....*

10.4.1.2. *It has to be fixed*

Predominantly, however, ADHD was viewed as a ‘problem’ and a ‘disability’ that needs to be cured. Participants frequently mentioned the impact of ADHD behaviour on their child’s inability to ‘achieve’ at school and ‘function properly’ in society. They believed academic achievement is the key to success in life, and everybody should strive for success. Participants perceived ADHD as an ‘impairment’ to achieving ‘success’. As Susan stated:

*We need to fix the problem. If he is not achieving at school what he is supposed to achieve and there is a problem, then do whatever it needs to be done to fix it ....*

Kate’s perspective was similar:

*We think ADHD is impairment to success. We think success is everything. You got to be successful in life, academically and financially successful. You need to achieve regular goals, family/wife/kids. So, this is impairment, something to be cured ... it has to be fixed.*

10.4.2. *Diagnosis as a relief*

10.4.2.1. *It’s not my fault*

‘Diagnosis as a relief’ was the vernacular that all participants expressed knowing that the condition was a ‘neurobiological disorder’ caused by ‘missing chemicals in the brain’, and so was not their fault. The diagnosis relieved them from anxiety and stress, and provided reassurance that they or their children were not ‘bad’ or ‘naughty’, ‘lazy’
or ‘stupid’. The relief was also closely linked with the sense that there is help available, as Cheryl expressed:

_I was pleased to find out that there was something we could do because my son was really struggling. So it was very good for us to find out what the cause was of his problem ... a big relief because he was clearly intelligent but he was clearly struggling._

Linda described her feelings after she was diagnosed with ADHD:

_I actually felt relief. I was relieved because I realised that I was neither mad nor bad. There was certainly evidence that made other people to feel that I was bad ... sometimes I thought am I crazy? People said I am rude, I am this and that, I am mad ... but I thought I had a good heart ... I am concerned about people’s wellbeing and I wanted to help ... now I know why._

The diagnosis served parents as a mean of validating their parenting skills. They felt relief from a burden of guilt about being bad parents who could not discipline their children. As Jo felt:

_{... relaxed, thankful, happy, probably validated. Along the way we tried couple of others because he had [son] learning difficulties despite his intellect, we had him tested various other types of psychologically tested. They said he had learning difficulties associated with eye sight tracking which is very common with ADHD ... but he had two other diagnoses that both said that I was an over protective mother that caused those hassles... so I was causing his problem. They said I was the problem, not him ... it was all my fault and he had nothing wrong with it. So when he was diagnosed very comprehensively to fulfil more than minimum criteria [for ADHD], or maximum whatever you could have, it was a validation for him and for me. For him it was giving a name and understanding of why he was different._

All participants had a biomedical understanding of ADHD and recognised it as a medical condition, but, did not perceive this condition as a mental illness. As Fiona (grandmother) described her grandson’s ADHD:

_He is missing a chemical that doesn’t allow his brain to do what he needs to do. His brain is seeking stimulation or lacking the ability ... it’s not an illness, but it’s a disability, because his body can’t do certain things._
Kate acknowledged that according to diagnostic criteria – the Diagnostic and Statistical Manual of Mental Disorder\(^2\), ADHD is a mental illness, but still she was reluctant to believe that her son had a mental illness:

*Well, ADHD is a mental health issue in the DSM 4 and 5. According to that he has, but I don’t think about it to be honest ... I don’t see him mentally ... but if not treated it can be a mental health issue ... [so] we accommodate for his [ADHD], so he won’t have any serious mental health [problem].*

While the participants were reluctant to accept ADHD as a mental illness, they accepted this condition as a disability. It appeared that the disability status of ADHD might serve some purpose for two of the participants. Annette who had two of her children diagnosed with ADHD, found that school staff were supportive and they understood ADHD as a disability, and accommodated her children’s needs with special care as necessary. She, however, became “frustrated” with the social security personnel who did not think of ADHD as a disability and so did not think Annette should be eligible for a caregiver allowance for children with disabilities. However, Linda who did not perceive ADHD as a mental health problem, but believed it is as a disability, was able to secure her disability pension for ADHD.

### 10.4.2.2. It runs in the family

The relief was closely tied with perceiving ADHD as a genetic condition and realising that it ran in other family members. The participants mentioned that after one child was diagnosed, they started noticing similar symptoms in their other children and in other family members. Three of the participants were diagnosed after their children were diagnosed. Patrick was one of them:

*My two older boys were diagnosed first, and listening to the paediatricians I realised that me and my wife had the same symptoms ... so it came through our lines, therefore it was genetic and heritage ran from us ... so we were treated.*

Annette defended herself saying that she tried her best to be a ‘good mother’ during her pregnancy and afterwards doing ‘everything right’ and confirmed that ADHD was not her fault but a genetic disorder.

*When I was pregnant, I did nothing wrong – no drinking, no drug, no bad food. I did everything by the book. I pumped myself from everything to be the best mother ... since*
they were little I gave them boundaries, they were not allowed to have soft drinks, sugar ... so, that was not the case ... it [ADHD] was from the family ... it’s genetic, it’s through the generation ... through the father ... while doing this [treatment for the first child] we sort of knew my husband had had it for a very long time. So we got him diagnosed ... it’s hereditary ... since my husband was diagnosed, my father-in-law with full of ADHD ... in his 60s ... said to me “I know I’ve got it”.

10.4.3. Responsibility

10.4.3.1. To be normal

Responsibility focused on parents’ abilities to solve the problem their child was experiencing at school and how stimulant medications helped the parents to fulfil their responsibilities. When describing the effect of medication, the parents and grandmother in the study placed emphasis on their child’s academic outcomes. The medication helped their child to ‘slow down’ and to engage ‘straight away’, which helped the child to ‘focus’, ‘concentrate better’ and ‘stay on task’ at school. The parents frequently mentioned that their child achieved higher grades after taking medication. Three parents said that the school teachers were also happy with the change in their child’s behaviour. For two parents, medications were believed to improve the ‘quality of life’ of the child. A few participants reported unpleasant effects of the stimulants, such as ‘mood swing’, ‘weight loss’, ‘decreased appetite’, ‘heart going faster’ and ‘trouble with sleeping’. They mentioned that their child was prescribed ‘Catapres’, which was usually prescribed for high blood pressure, to reduce the side-effect of the ADHD stimulants. All parents acknowledged stimulants as the most ‘evidence based’, ‘effective’ treatment. Four recognised the stimulant as an ‘important part’ of the ADHD treatment strategy, but as only ‘a part’, and said that their child also required psychotherapy, counselling, learning and behavioural management.

All parents reported in initial hesitation about using stimulant treatment, and expressed concern that the medication was ‘not good for health’. The grandmother mentioned that her initial resistance to medication was due to ongoing debate in the public sphere about over-diagnosis of and over-medication for ADHD. Two parents exhausted other alternative therapies before they agreed to stimulant medication. As Cheryl noted:

... it’s not the decision that parents make easily. Any long term medication that you put your child on – this is something you have to think about long and hard. You have to
Parents felt it was their responsibility to boost their child’s ‘self-esteem’ to make them feel ‘normal’, so that they could ‘fit in’ society. Annette felt ‘strange’ with the idea of giving medication to manage behaviour initially; however, she convinced herself, thinking that giving stimulants to her children for ADHD was similar to taking blood pressure medication for herself. As such, she realised that she must not feel guilty about giving the ADHD medication, because it was her responsibility as a ‘good mother’ to help her children to improve their self-esteem and to allow them to fit into the community. As she articulated: 

*I felt strange … but now it is a normal way of life and I don’t have a problem with it. So I don’t feel guilty about giving [medication] to them [the children]. As a parent, it is my responsibility to give them … it is no difference to my blood pressure tablet. I have to take blood pressure tablet or I would feel ill. ... So, it’s [medication] a tool for them to cope. To me, it’s a tool to not feel inadequate, not feel different. I don’t want them to be in trouble. I don’t want them to feel that there was something wrong with them ... it’s about self-esteem, confidence ... about fitting in ... learning, adaptation. ... So they have their routine, and they have to take the medication every day to be normal.*

In many instances within the interviews the participants defended others’ perceptions of their ADHD behaviour or that of their children. They took a proactive approach to educate people about the nature of ADHD and the role of medication. They tried to move beyond what other people perceived about themselves and also any feeling of guilt that troubled them about giving medication to their child. They appeared to be justifying their decision to adhering medication treatment. They advocated for ADHD as a disability and the use of medication as an acceptable treatment choice. They believed that by educating others they would normalise ADHD, destigmatise stimulant treatment, and improve the outcomes of their and their child’s ADHD. Through this role, they constructed themselves and their child as normal. Patrick and Cheryl took on the position of educators for managing ADHD and stimulant treatment. Annette raised
money for an ADHD charity. She and her husband, who was also diagnosed with ADHD, “proudly wear t-shirts writing on it – ‘ADHD makes me with a super power’, ‘I’ve forgotten my meds today’ so that [their] kids have a role model”. Annette also worked hard to educate other parents and children about ADHD so that other children would find her children ‘normal’ and ‘average’. As she described: 

So I try to make it open as much as possible. I brought the book, and the teachers read with other kids that [her son’s name] has a brain, and he can’t concentrate. So the whole class would know that’s how the teacher is educating the children. There is nothing wrong with [her son’s name] he has taken medication to calm down. So if the parents think that way, it should come from the children that [her son’s name], is not naughty, not a bad kid and he does not have any problem. I used to bring all books and DVD on ADHD and gave it to teachers to give it to other parents, because I wanted to have others to be educated.

10.4.3.2. To fit in

Susan also expressed her concern about giving medication to her child, but she justified her decision by saying that as a ‘responsible mum’ it was her duty to make her son fit into school and, therefore, she needed to continue with the medication. To minimise the harm of the medication and to allow her son to ‘learn to be himself’, she gave him a break from medication on school holidays.

I feel I am doing the right thing, but I wish I didn’t have to ... I don’t like it [giving the medication], but I have to do it for his education. It’s a drug and it is not good for your body, ... so on school holidays I don’t give it to him, he doesn’t need it for any reason, because he is what he is, so he can learn to be himself without the pill ... but he has to go to school and do what he is told to do and to fit in. If he was diabetic, he had to have the medication. So I feel to be a responsible mum, he has to have it. I can’t have him the way he wants to be ... that’s not responsible parenting ... that’s wrong ... giving him wrong expectations – so he has to take the pills ... responsibility is you have to do what you have to do. If he is happy with his life later not to take it that would be his adult decision, [but] I will guide him until then.

Susan, however, did not get her older son, who she thought also had ADHD, diagnosed and treated, because his condition was not affecting his education. She thought because he was ‘getting away with his school work’, she did not need to ‘medicate’ him.
Through comparing ADHD medication to that taken for chronic diseases, such as diabetics or blood pressure, the parents emphasised the medication’s role in their child’s future – perceiving it as an investment for their child’s academic career, despite giving medication being an unpleasant feeling for them. Thus, they constructed themselves as a ‘good parent’ which allowed them to resolve any feelings of guilt about giving medication.

For the adults with ADHD, taking medication was also about a responsibility to ‘fit in’ at work, within family and in relationships. They experienced improvement on everyday activities, organising tasks at work, interpersonal skills and having meaningful conversations like ‘normal people’. They found their family and friends coped better with them when they were on medication. As such it was their responsibility to fit in with family and society. As Susan, who was also taking medication for ADHD, reflected:

*I take my pill to cope with pressure … I could cope with the world … if I didn’t take the pill I wouldn’t be able to talk to you like this … wouldn’t be able to focus at work … my husband copes better with me when I am on the pill … so I have to [take medication], to stay in the relationship, to keep our life easy.*

10.5. DISCUSSION

The findings of this exploratory study assist in understanding the complexity of ADHD. The results consisted of interrelated yet sometimes contradictory themes that depicted the participants’ views of ADHD and stimulant treatment, and in turn influenced the participants’ decision making process to adhere stimulant treatment. There were three overarching themes: an impairment to achieving success, diagnosis as a relief and responsibility. The findings from this study reflect the ontological and epistemological assumptions of the social constructivist framework which assumes that across individuals there may be multiple understandings of phenomena, being in this instance ADHD and attitudes towards its treatment with stimulant medication. It was notable that the themes were defined and redefined by participants particularly through their everyday interactions with others in a community setting.

ADHD is perceived to be an impairment to achieving success reflected in two sub-themes: ‘it’s a double-edged sword’ and ‘it has to be fixed’. The expression ‘double-
edged sword’ in this study bares similarity to observations made in a UK study, where Singh et al.\textsuperscript{381} noted that young people with ADHD expressed a dichotomous sense of themselves. They felt that their ADHD behaviour was ‘fun’, but then acknowledged that their fun behaviour was ‘annoying’ to others. The participants in this study perceived ADHD as fun, challenging and interesting; however, when comparing the fun behaviour with the perceived obstacle to achieving success, and particularly academic success, they chose to accept ADHD as an impairment which had to be ‘fixed’.

![Diagram](image)

Figure 16. Perception towards ADHD and stimulant treatment choice

The participants had a biomedical understanding of ADHD, ascribed to it a causal relationship with academic under performance\textsuperscript{4} and accepted stimulant medication as the eventual treatment of choice, albeit sometimes after seeking alternatives or as the mainstay of a broader treatment strategy. This was in line with a help-seeking behaviour model for ADHD, which suggests that the individual’s perceptions about ADHD influence their treatment choice\textsuperscript{65}. Our findings resonate with those from Canada where Johnston et al.\textsuperscript{158} identified that people’s degree of acceptance of a medical aetiology of ADHD was significantly associated with stimulant treatment choices. The participants in this study were Caucasians, relatively affluent and well
educated. Understanding ADHD as a medical condition and accepting stimulant treatment to improve academic performance is comparatively more common among Caucasian families than in other ethnic groups in the US and UK\textsuperscript{239,335}. However, when a child’s academic achievement seemed to be threatened by ADHD, people from other cultural and ethnic background were also found to accept stimulant treatment. Korean parents who tended to take personal responsibility for their child’s ADHD behaviour and had initial negative attitudes towards medication treatment, were reported to administer stimulants once they believed that ADHD was associated with their child’s relative lack of academic achievement\textsuperscript{240}. In a study in India, the findings suggested that parents who resisted a biomedical explanation of their child’s ADHD behaviour tended at first to seek religious help to minimise the impact of the ADHD. The same parents, however, sought medical interventions when they perceived that problems with their child’s academic performance were not improving\textsuperscript{242}.

Participants in this study described a sense of relief following diagnosis, as it provided them with an explanation for the difficulties they or their child had experienced. The sense of relief stemmed from the fact that the diagnosis reassured them that the problem behaviour was not a personal failing in any moral sense, but rather a mental or at least cognitive disorder. In a phenomenological observation study of eight adults with ADHD in the UK, Young et al.\textsuperscript{382} also reported that the diagnosis eliminated an individual’s sense of failure as their ADHD behaviour could be explained and attributed to a specific disorder. The parents in this study tended to defend themselves, saying that they did their best to be ‘good’ parents and so the parenting was not the cause of their child’s ADHD. As such, the diagnosis validated child’s problem behaviour and school failure what not a reflection of failed parenting. These findings have parallels in another study by Singh\textsuperscript{383}, conducted in the UK and US among 153 children and their parents, for whom the diagnosis provided a great relief. Parents (mothers especially) with an ADHD child often walk a fine line between perceiving themselves as ‘good’ and ‘bad’ parents, because they are most often blamed for their child's misbehaviour and under achievement\textsuperscript{220,384-385}. Hence, scholars argue that although parents use the biomedical model of aetiology of ADHD to provide some relief from parental blame, the medical model may not serve to provide total relief from feelings of personal responsibility, stress, anxiety and guilt\textsuperscript{358-383}. As Taylor et al.\textsuperscript{360} noted, in an attempt to make the right decision for their child about the stimulant treatment, parents go through
several stages in which they face contradictory societal attitudes, such as parental blame for their child’s misbehaviour on one hand, while also experiencing anxiety and guilt feeling about drugging children by administering stimulants. To cope with the stressors of raising ADHD children and the associated societal pressures, parents tend to defend themselves by employing strategies like advocacy, education and strategic difference, all of which are congruent with the findings from this study.

Parental concern about the potential long-term side effects of stimulant medication was observed in another study in the US, where parents of children with ADHD expressed fears and accepted stimulant treatment reluctantly, even though they agreed that the medication helped their child. Despite being worried about long-term effects and some immediate unpleasant side-effects of stimulant medication, parents in this study felt that it was their responsibility to continue with the medication to improve their child’s self-esteem by helping the child feel normal and to ‘fit in’ with the community. Whilst results have been reported where parents discontinued stimulant treatment in their child’s best interest due to uncertainty about long-term effects on brain function, related stigma and the child’s disliking of use, the present findings are more consistent with those of Hansen and Hansen, who found that parents tolerated the medication’s side effects and risks in the hope that it would play an important role in enabling the child to attain their academic goals and achieve success in their adult life.

Parental effort to improve their child’s academic performance and boost self-esteem is a rational consequence of the fact that higher education is a critical path to one’s career success in modern society. To achieve career success, an individual is required to develop competency across a wide range of personal qualities, which may include self-esteem. While some investigators have found no influence of self-esteem on relationship or career success, others claim that a high level of self-esteem is crucial for success and life satisfaction in these spheres. Whether one’s self-esteem serves career success or not, self-esteem is valued in today’s society, and developing children’s self-esteem is reportedly evident as a cornerstone of contemporary Western parenting practices, particularly in middle class families. In a qualitative study using semi-structured interviews with Canadian parents of children seen as cognitively impaired (including some with ADHD and learning disabilities) and those with unimpaired children, Ball and Wolbring found that parents would consider
stimulant use if they perceived their child was struggling at school, failing to fit in or had low self-esteem. The parents in their study believed that it was their responsibility as good parents to make their child feel normal and encourage them to succeed in life.

The adults diagnosed with ADHD in this study also referred to their needs to feel ‘normal’, to have the ability to interact with other people, to belong in the community and to be accepted by family and friends. These findings are consistent with other studies where adults with ADHD perceived that being accepted by others as a normal responsible social being was important\(^{382,400}\), and that the medication enabled a sense of normality and social belonging to occur\(^{382,401}\).

The findings from this study suggest that individuals’ perceptions and experiences shared much in common in the general sense, yet in detail the individuals’ journeys had been diverse and complex. The findings underline that a person’s understanding of ADHD behaviour and their attitude towards stimulant treatment are important considerations in selecting an appropriate intervention and in developing policy on the regulation of stimulant treatment use. Individuals who do not experience the perceptions of difficulties in academic performance or fitting in with society may not necessarily seek stimulant treatment, even if it would be beneficial from an objective viewpoint. This was noted in the interview with Susan, who thought that her older son also had ADHD, but did not seek treatment for him because he was achieving school grades to her satisfaction. On the other hand, desire to accelerate academic performance may motivate individuals to pursue the non-medical use of stimulants\(^{352-402}\). Parents were hesitant to use stimulant medication initially due to long-term side effects, but administered it as they were concerned about their child’s academic under performance, self-esteem or failing to be ‘normal’. More parents may consider stimulant medication if they perceive these drugs as less harmful or if cultural trends redefine what is normal.

This study contributes to the body of literature with its focus on individuals’ perceptions of ADHD and attitudes towards stimulant medication, including perceived roles of medication in child’s future. Paying attention to perceptions of ADHD and reasons for seeking or not seeking stimulant treatment is important when planning appropriate interventions for this condition to avoid over-diagnosis and overtreatment. The findings reinforce the need for more education of medical professionals to enable them to plan
appropriate interventions and to give appropriate support and guidance to optimise outcomes for individuals with ADHD and their families.

There are some limitations to this study that deserve consideration. Firstly, the participants in were white, middle class people, living in a metropolitan area. As such, their perceptions may not reflect those of community members from other backgrounds, highlighting the need for research among culturally and ethnically and socioeconomically diverse groups in the future. Secondly, as the sample was largely female, the views of a wider range of males were somewhat absent from the research. Thirdly, three of the four adults with ADHD were parents who were diagnosed after their children had been diagnosed, and mostly described their experience as being parents. Even though the experience of one adult with no children was little different from the parents diagnosed with ADHD, findings drawn from this sample may not be transferrable to the perceptions of ADHD and stimulant treatment of adult patients. Fourthly, given the nature of qualitative analysis, this study represents only one interpretation of the participants’ experiences, hence it delivers a partial, static picture of their perceptions of ADHD behaviour and attitudes towards stimulant treatment. Further, the analysis primarily denotes interpretations made by a single research group with the possibility that others might draw different inferences. Despite its limitations, this study does provide some important data with respect to the factors that shape individuals’ attitudes towards ADHD and influence individuals’ treatment choices. Building on these insights, further research can be conducted in a format that would canvas a wider range of views. Future research could also include a multi-perspective and longitudinal design, interviewing children, young adults and their parents to explore evolving perceptions of ADHD and medication over time.

10.6. CONCLUSION

The participants in this study perceived ADHD behaviour as an impairment to achieving success in life. A desire for academic achievement, good self-esteem, being normal and a sense of belongingness were important driving forces for stimulant treatment use among parents of children diagnosed with ADHD. Adults diagnosed with ADHD found stimulant medication was important for a responsible person to fit in to the community. The findings have potential to be used to raise awareness and understanding among medical practitioners working with ADHD adults, children and
their parents of the perceived reasons why patients seek or do not seek stimulant treatment.
DISCUSSION AND THESIS CONCLUSIONS

11.1. INTRODUCTION

This thesis explored differentiating patterns of prescription stimulant medication use for ADHD treatment in the WA community. The thesis is divided into two distinct parts – Part A and Part B, and employed both quantitative and qualitative research methods. Part A explored sociocultural disparities in stimulant medication use from 1 January 2003 and 31 December 2007. This quantitative phase consisted of two sequential parts. The first part explored the impact of parental country of birth and race on the use of psychostimulant use which then informed the second quantitative study to investigate individuals’ own country of birth influence on stimulant use for ADHD. The quantitative findings in Part A collectively informed the qualitative phase in Part B which explored individuals’ perceptions of ADHD behaviour, the meaning that the diagnosis carries for them and their attitudes to stimulant treatment.

A discussion and integration of Part A quantitative and Part B qualitative findings is presented in this final chapter. The chapter starts with a discussion of the strengths of the study. An overview of the major findings then follows. Limitations of the study, implications of the thesis findings, and future potential areas of research are presented followed by a conclusion.

11.2. STRENGTHS OF THE STUDY

Please note that the limitations of the study are covered extensively in section 11.6, after the personal reflection in section 11.5.

11.2.1. Study design

A strength of this thesis is the use of quantitative and qualitative research design, which offsets to some degree the specific weaknesses of both quantitative and qualitative research methods. The combination of both quantitative and qualitative methods has
provided a more comprehensive evidence base for understanding the differentiating patterns of stimulant medication use for ADHD than could have been achieved using either research method alone. The quantitative studies examined the pattern of stimulant use in population subgroups from different cultural backgrounds, with a higher use observed in individuals or their parents born in predominantly Anglophone nations. The qualitative study examined the possible reasons for the higher propensity for stimulant use in those subgroups by exploring how they perceived ADHD behaviour and stimulant medication treatment. The triangulation of the two methods afforded greater freedom to employ multiple paradigms or worldviews to explore the issues.

11.2.2. High quality health administration data

Another strength of the analysis was the novelty of the WADLS as enabling research infrastructure. It amalgamated records belonging to the same individual from different sources. It provided reliable information on stimulant prescriptions dispensed for ADHD, individuals’ and parental countries of birth, socio-economic status and residential remoteness through integration of data from the WA Birth Registrations, HMDC, MNS, MODDS and Death Registrations databases, covering the entire population in WA dating back as far as 1966. The quality of the linkage has been extensively validated, whereby a sampling technique estimated both the percentages of invalid links (false positives) and missed links (false negatives) to be 0.11%. Hence the internal validity of the research was enhanced by the quality of these linked data.

11.2.3. Family connections genealogical data

This is the first genealogical study to pursue an objective in social epidemiology, using the WAFCGS to employ parental country of birth as a marker of cultural heterogeneity. The WAFCGS has been also extensively validated and has created significant research possibilities by increasing the accuracy of families pedigrees and associated risk assessments to guide medical decision making. As the genealogy database has the ability to identify genealogical links between individuals in the WA population, it has become the primary source of information for WA genetic epidemiological research on inherited characteristics in human populations. The work in this thesis demonstrates the potential for applications of the WAFCGS in social epidemiology, in this case by using genealogical information on parental country of birth and race to
explore the broad effects on utilization of possible cultural differences in knowledge, health practices and behaviours surrounding ADHD symptoms.

11.2.4. Large sample size

A large population-based cohort of nearly 700,000 people born or hospitalised in WA over a 27-year period (1980-2007) provided data to address the research objectives. The sample included a sufficient number of Aboriginal people for an Aboriginal subgroup analysis and also enabled comparisons between ADHD and non-ADHD groups. The large sample size resulted in good precision of the estimates in this thesis with narrow 95% confidence intervals around the measures of association. Given that the WA population is adequately representative of Australia as a whole, the large sample size maximises the generalisability of the analytic findings Australia-wide. The findings add to the literature, particularly for the Australian population, where there is no previous published research on cultural disparities in stimulant medication use for ADHD treatment. Internationally it contributes to emerging evidence of the existence of ethnic differences in stimulant use from the southern hemisphere.

11.2.5. Internal validity

As mentioned earlier, the linked data enhanced the internal validity of the study by reducing systematic errors arising from misclassifications of exposures and outcomes at least on the basis of the data that were available. The internal validity was also assisted during data analysis by the use of multivariate logistic regression, cox proportional hazards regression and linear regression models to reduce systematic error arising from potential confounding factors.

11.3. INTEGRATION

This section describes and integrates Part A and Part B and proposes a model for stimulant medication choice for ADHD treatment. Figure 17 illustrates conceptually the findings from quantitative and qualitative research and the relationship between the findings towards stimulant treatment choice. Individuals’ perceptions, knowledge and understanding of ADHD were fundamental in decision making for ADHD medication treatment. Perspectives and knowledge were interrelated with individuals’ residential, and socioeconomic status, as well as desire to achieve success and to fit into society.
Investigating differentiating patterns Part A revealed cultural and racial disparities in stimulant medication use in WA. These disparities were due to cultural perspectives, knowledge and understanding of ADHD behaviour. Geographic location and socioeconomic status also added to these disparities in stimulant use in WA. Part B, confirmed perspective, knowledge and understanding as the prime factors for stimulant use. Part B further revealed that the desire to succeed in life and to fit into society motivates individuals to adhere to stimulant medication.

Figure 17. Model for stimulant treatment choice

11.4. OVERVIEW OF MAJOR FINDINGS

While the results from quantitative studies in Part A, and qualitative study in Part B were discussed in detail in Chapter 5, 6, 7 and 10, it is important to revisit the major findings here to consider the interconnections with the overall thesis findings.
11.4.1. Country of birth influences on stimulant medication treatment

As outlined in chapters 5 and 7, individuals or their parents born in LPNO/non-Anglophonic countries were significantly less likely to have stimulant medication for ADHD treatment compared with their HPNO/Anglophonic counterparts. Individuals with two LPNO/non-Anglophonic parents were 83% less likely (OR=0.17, 95%CI 0.14-0.21) to have stimulant medication treatment and those with just a LPNO father were nearly two-fold less likely (OR 0.53, 95%CI 0.47-0.61). Similarly, LPNO/non-Anglophonic born individuals were about one half as likely to receive stimulant medications compared with their HPNO/Anglophonic born peers (OR 0.53, 95%CI 0.46–0.61, p<0.001). Individuals’ beliefs about ADHD and stimulant medications influence their treatment choices, either for their children or for themselves\(^{65}\). How an individual internalises normal and pathological behaviour and how they respond to behavioural problems are largely determined by that individual’s cultural beliefs and perceptions\(^{61}\). Parents from LPNO backgrounds compared with parents from HPNO/Anglophonic backgrounds are less likely to accept ADHD as a medical condition, and therefore, are reluctant to accept stimulant medication treatment for their child’s ADHD behaviour\(^{55,409}\). Individuals and parents from LPNO cultures do not perceive ADHD as a pathological behaviour, instead attributing many of its symptoms to a natural phase of childhood development\(^{165,176,240,296,330}\) and preferring non-pharmacological interventions\(^{55,242}\).

11.4.2. Delayed onset of stimulant treatment according to culture

The mean age at onset of stimulant treatment in those from a LPNO background was 1-3 years older (13.31 vs 12.48, 14.98 vs. 12.27 years after adjustment, p<0.001) than in those from a HPNO background in this thesis (Chapter 4 & 6). A different cultural perspective in understanding ADHD behaviour and stimulant treatment is the possible primary reason for delaying stimulant treatment in individuals from LPNO backgrounds. Parental fears of embarrassment and the cultural stigma associated with mental illness and psychiatric treatment have been observed also in the Iranian\(^ {178,329}\), Latino\(^ {94,165}\), Asian\(^ {241}\), Moroccan, Surinamese and Turkish\(^ {410}\) and Indian cultures\(^ {177,242}\), leading to delays in stimulant treatment for ADHD. The results in this thesis (chapter 4) suggest that having a LPNO father, in particular, reduces the likelihood and delays the onset of stimulant treatment for ADHD, possibly due to a higher treatment threshold.
among fathers, especially for their son’s ADHD behaviour\textsuperscript{155,295}. In some LPNO countries, fathers are the dominant decision makers on child health issues and concerns over costs could be another possibility for a delay in stimulant treatment in individuals with a LPNO father.

11.4.3. Variations in the stimulant treatment use according to Aboriginal status

Results of the Cox regression analysis in chapter 6 showed that individuals with two Aboriginal parents were two-thirds less likely (HR 0.33, 95%CI 0.26-0.42, \(p<0.001\)) to have stimulant treatment, compared with individuals of Australian born, non-Aboriginal parents. Stimulant use was notably lower in individuals of Aboriginal mothers with one-third less (HR 0.69, 95%CI 0.53-0.90, \(p<0.005\)) compared with individuals of non-Aboriginal parents. Unlike the first study in chapter 5, where LPNO fathers were associated with a reduced likelihood of stimulant use, having an Aboriginal mother had the strongest apparent influence on reduced stimulant use, an observation consistent with other evidence that the mother, more so than the father, plays a central role in caretaking and decision making for children in Aboriginal communities in Australia\textsuperscript{263,318}.

Understanding of ADHD and attitudes towards medication treatment in Aboriginal parents may account for the lower stimulant treatment for ADHD in Aboriginal children and adolescents. Aboriginal parents may perceive hyperactivity and impulsivity as a normal part of a child’s upbringing, as they allow their children freedom to explore their environment with relatively few restrictions and boundaries, in order to makes them physically and emotionally resilient and to develop their own controls\textsuperscript{313}. Perceived fear and mistrust towards western health practitioners and treatment\textsuperscript{266} are among other possible explanations for a lower propensity towards stimulant treatment. Many Aboriginal people also believe that the western medical system is culturally inappropriate to their needs, because it does not incorporate or respect Aboriginal’s world view\textsuperscript{261-262}.  

162
11.4.4. Disparities across gender, socioeconomic status and residential remoteness in stimulant treatment

There were several other salient observations made in this thesis. The first was to confirm the well-known gender disparity in stimulant use. There was an uneven distribution of ADHD treatment in this study, possibly due to gender variation in ADHD manifestations, where boys exhibit more hyperactivity and impulsivity than girls, who commonly display a less active form of inattentiveness. Gender stereotypes may influence clinicians to over diagnose more boys than girls, even when criteria are not fulfilled. As ADHD is considered an impairment to academic performance, boys’ externalising behaviours in a classroom environment may become uncomfortably disruptive, influencing teachers to make ADHD referrals for more boys than girls and thus contributing to the imbalance through a referral bias.

The second observation, the association between socioeconomic hardship and increased stimulant use in this study, was consistent with previous work. A greater prevalence of ADHD symptoms in marginalised children and adolescents with low educational attainment, unemployment and reduced access to social supports is well established. A large proportion of children and adolescents in Australia living in poverty were reportedly being treated without having met the ADHD diagnosis criteria. Yet, contrary to the overall findings and previous research, the results in chapter 5 also found no association between disadvantage and stimulant use within Aboriginal children and adolescents. This novel result may require further investigations.

The third observation, being the geographic disparity in stimulant use, was also well-known beforehand. Individuals living in metropolitan areas compared with their rural peers were more likely to receive stimulant treatment in this study. This can be explained by greater availability of physicians and specialised healthcare services in major cities. Differences in lifestyle, beliefs about problem behaviour, and attitudes to stimulant treatment are also possibilities that might contribute to a regional disparity in stimulant treatment for ADHD.
11.4.5. Individuals’ perceptions of ADHD and attitudes towards stimulant treatment

The analysis of qualitative data in chapter 10 identified three overarching themes with two sub-themes for each: (1) Impairment to success: ‘it’s a double-edged sword’, ‘it has to be fixed’; (2) Diagnosis as a relief: ‘it’s not my fault’, ‘it runs in the family’; and (3) Responsibility: ‘to be normal’, ‘to fit in’. The themes, while they were often interrelated as participants shared their attitudes and perceptions, were sometimes directly contradictory to one another, thus underlining the complexity of the topic. In general, participants had an understanding of ADHD behaviour as a medical condition and perceived ADHD as an impairment to one’s academic and professional success in life. Consequently, they accepted stimulant medications as an effective treatment choice to improve ADHD behaviour, to improve academic performance, to be accepted by the community as ‘normal’, as well as to boost the self-esteem needed to achieve success. All participants in this exploratory study were Caucasians living in the Perth metropolitan areas. The participants’ understanding of a bio-medical aetiology for ADHD provided a possible explanation for the higher stimulant medication use in individuals with Anglophonic (HPNO) backgrounds in this thesis (Chapter 4-6). The findings resonated with those reported from studies conducted in the US\textsuperscript{55,239} and UK\textsuperscript{335,381}, where Caucasian families were more likely than non-Caucasian families to perceive ADHD as a medical disorder and to accept stimulant medications for the treatment of the disorder.

11.5. PERSONAL REFLECTIONS

As my doctoral journey reaches its destination, it is time to glance back over the vast experiences gathered through the long distance travelled, and to reflect on it. This research journey represents an exceptional opportunity to explore the patterns of stimulant medication use for ADHD treatment in WA and the factors associated with the differentiating patterns. Moreover, this journey signifies a discovery of the phenomenon of ADHD through the lenses of those who have lived experiences with ADHD.

Reading through the existing literatures on ADHD, as outlined in Chapter 2, I prepared myself to interpret the findings without being judgmental. Although I was overwhelmed and alarmed by the sheer volume of scientific papers and contradictory
theories of ADHD and medication use, I have come into the realization that there is no single right or wrong perception towards ADHD behaviour, neither is there a single correct treatment for this behaviour. What made me uncomfortable however, are the qualitative findings which revealed that individuals were inclined to adhere to stimulant treatment when they perceived academic success or fitting in the society were threatened due to ADHD. Is there a possibility that desire to enhance academic performance or perceived failure to be normal may lead an individual to use stimulant medication beyond ADHD? As outlined in Chapter 8, the use of stimulant medications to enhance cognition and academic performance is a recent social trend possibly led by globalization of ADHD and stimulant treatment, which Oldany43 criticised saying, “within the domain of modern medical and biopsychiatric practice, as well as pharmaceutical industry sales practices, the idea and reality of … families exists somewhere between that of the neurochemical self and psychopharmacological societies.” (p. 134). In an Australian study353 of 1,265 participants, 7% agreed that cognitive enhancement was acceptable, and 3.6% of participants agreed that performance-enhancing drugs in professional sports should be allowed. The participants who found cognitive enhancement acceptable were 9.5 times more likely to agree with legalized doping. The findings pose an ethical concern.

11.6. LIMITATIONS

11.6.1. Cohort selection

A major limitation of this thesis was the cohort selection for the quantitative research. Stimulant use was ascertained on the basis of records of stimulant prescription dispensing for ADHD in the general population, which was then stratified into various subgroups according to ethnic and other socio-demographic factors. Thus the study was effectively concerned with cultural differences in treatment utilisation without the availability of diagnostic information. It is possible that the prevalence of ADHD symptoms varies for biological rather than cultural reasons between the HPNO and LPNO subgroups. It is also possible that individuals from LPNO background are diagnosed with disproportionately lower rate than individuals from HPNO. It would have been ideal to enrol a cohort of people who each had a diagnosis of ADHD established by consistent, objective criteria and then to observe stimulant vs no stimulant use according to country of birth and the other factors within those with the
same clinical manifestations. The datasets, however, did not contain the information to identify individuals diagnosed with ADHD, but not ever treated with stimulant medications; nor was any form of population-based register of ADHD diagnoses available anywhere in the State. While developing a datasets to identify individuals diagnosed with ADHD and not treated with stimulants is recommended, it is possible that individuals only get diagnosed with an intention to be treated with stimulant. Despite this limitation in the cohort construction, the three studies (Chapters 5-7) yielded similar results, demonstrating evidence-based cultural disparities in ADHD diagnosis and stimulant treatment in WA.

11.6.2. Completeness of linked health administrative data

There are some general limitations to research using linked health administration data, which should be taken into account. These include insufficient specification of subgroups, valid comparisons and non-ascertainment of study outcomes, even though the completeness of hospital morbidity data collection is very high (>99%) in terms of demographic information, primary diagnoses and procedures. The MODDS has routinely collected data on both prescribed and dispensed stimulant medications, along with patient information, within WA since 2003. The data analysis in this thesis, therefore, is expected to provide accurate estimates of prescription stimulant dispensing patterns for ADHD in WA during 2003-2007. However, unlike the quality of linkage procedures in the WADLS, there was no formal validation or clerical audit of the completeness of the stimulant medication data since the promulgation of the MODDS regulations. Therefore, caution is suggested when interpreting the results in this regard. Besides, as the stimulant data were only available from 2003, it was possible that the first record in the MODDS dataset between 2003 and 2007 was not the first stimulant record for ADHD in an individual’s life.

11.6.3. Individual's ethnic information

Information of individuals’ or parental ethnic backgrounds for studies in chapter 4 and 6 was unavailable. As such, I substituted country of birth for ethnicity to examine cultural influences on stimulant use. While an individual’s country of birth may impact on how people perceive stimulant treatment for ADHD, reliance solely on country of birth information could misrepresent an individual’s true cultural perceptions and
beliefs. Having access to both ethnic and country of birth information would be ideal to examine cultural influences on individual perceptions. For example, in the qualitative study (Chapter 7), one participant was born in South Africa, but was better classified as Caucasian in that study. The participant would have been classified as a LPNO parent in the quantitative study (Chapter 4). This limitation in the measurement of parental ethnic identity may have influenced the findings of the analysis.

### 11.6.4. Individual's migration status information

Information on parental or individuals’ migration status or length of stay in Australia could not be obtained. Therefore, it was impossible to determine if the lower use of stimulant medications in LPNOs was due to culture or obstacles that immigrants often experience, which may have restricted them from accessing ADHD services.

### 11.6.5. Accuracy of Aboriginal data

An individual’s Aboriginal status recorded in the administrative datasets was based on self-identification. If an Aboriginal person decided not to identify themselves as Aboriginal or Torres Strait Islander, then the true count of such individuals would be an underestimate. In order to maximise the sensitivity of identification of Aboriginal people in this study, information on Aboriginal status was collated from multiple sources such as the birth registry, MNS and HMDC with Aboriginal status being recorded in any one data set being sufficient. However, it was still possible that Aboriginal people were under-reported or misreported due to the fact that people may not be prepared to disclose their Aboriginal status for the purpose of records in any of the databases.

### 11.6.6. Small sample size

While a sample size is not exclusive to qualitative research which seek to gain a deeper understanding of individuals’ perceptions through experiences, its particular implications could be. The aim of the qualitative study in Chapter 9 was to seek to understand some of the reasons behind the finding of the two quantitative studies which explored both parental country of birth as well as individuals’ own country of birth influences on stimulant use for ADHD. As such I tried to recruit two fairly
representative samples who themselves were diagnosed or had dependent children diagnosed with ADHD. However, I found it hard to access a population to offer me insights about their ADHD diagnosis and stimulant treatment. Perceptions of stigmatising experience towards ADHD often restrict individuals from being open up to talk about this issue\textsuperscript{243}. Findings drawn from only eight participants who were parents of children with ADHD or were adults who themselves had been diagnosed with ADHD may not be adequate to generalise the perceptions of ADHD and stimulant treatment of those two groups.

11.6.7. Absence of participants from socioeconomically and geographically diverse background

The participants in the study were middle class Anglophonic with higher education and living in the metropolitan areas. While there were some contradictions in their perceptions towards ADHD and stimulant treatment, they all had a biomedical understanding of ADHD. Their perceptions may not be transferrable to the perceptions and understanding of ADHD and attitude towards stimulant medication to other Anglophonic Australians from socioeconomically and geographically diverse background.

11.6.8. Absence of participants with culturally diverse background

I expected to compare individuals’ perceptions and attitudes to ADHD and stimulant treatment between people with Anglophonic and non-Anglophonic backgrounds in the qualitative study. Having both Anglophonic and non-Anglophonic people would have enabled me to explore cultural differences in the expectation, diagnosis and treatment of behaviours associated with ADHD, as well as the reasons for the discrepancy in the use of stimulant treatment between the two groups as were observed in the quantitative studies. Participants from non-Anglophonic backgrounds would have also enabled me to determine if there was a reluctance among them, and to explore the reasons for the reluctance to take up stimulant treatment for ADHD. Despite repeated attempts and a wide circulation of the participant recruitment flyer and efforts at recruitment through snow-balling, only a handful parents with ADHD children and an adult diagnosed with ADHD from Anglophonic backgrounds responded to participate. Perceived stigma towards ADHD and stimulant treatment in ethnic minorities\textsuperscript{243-245} could be the possible
reason for lack of response from culturally diverse people to participate in this study. Due to the absence of non-Anglophonic participants, the perceptions of ADHD and attitudes towards stimulant medication treatment cannot be generalised to a wider community, in particular among communities from culturally and linguistically diverse backgrounds.

11.6.9. Absence of Aboriginal participants

The Aboriginal study was a subset study of the broader project and was not in scope when the thesis proposal was developed. Upon exploring country of birth differences in stimulant medication use, I came across an interesting pattern of stimulant use in Aboriginal data when I separated individuals who identified themselves as Aboriginals, Torres Strait Islander and/or Pacific Islanders from individuals who identified themselves as non-Aboriginals in Chapter 5 and Chapter 7. Accordingly I sought after an ethics approval from the WA Aboriginal Health Ethics Committee to enable me to conduct a quantitative study using the anonymous Aboriginal data. This process required several rounds of correspondence with the ethics committee regarding ethical conduct in Aboriginal health research. It took seven months to obtain the additional ethics approval. The quantitative study in Chapter 6 identified the needs for future research examining Aboriginal perception of ADHD. Even though the Aboriginals who are born in Australia, their perception of mental and behavioural disorder are expected to be different from the perception of white Australians or other ethnically diverse populations. Involving Aboriginal participants in the qualitative study could have been ideal. However, given the limited time of my doctoral candidature, I found it impractical to wait for any longer to obtain another ethics approval to conduct a qualitative study involving Aboriginal participants.

11.7. IMPLICATIONS OF THESIS FINDINGS

This thesis pointed out the cultural differences in ADHD treatment using stimulant medication in WA contributing to the body of knowledge in cultural disparities in stimulant treatment worldwide. This is the first attempt to compare stimulant use in Australian born Aboriginal and non-Aboriginal providing a pattern of stimulant use in the Aboriginal population in WA. Moreover, the thesis aimed to provide authentic accounts of how individuals, who themselves or their children were diagnosed with
ADHD, perceived ADHD and stimulant treatment. In this respect, the thesis attempted to listen to them and give voice to the individuals who were experiencing ADHD every day and dealing with the phenomenon of ADHD, and whose voice has been silent within the ADHD literature. Further implications for ADHD related policy and practices are as follows.

11.7.1. **Health policy and practice implications**

Given the lower rates of stimulant medication use for ADHD treatment for individuals or their parents born in non-Anglophonic countries, as compared with individuals or their parents born in Anglophonic countries, policy and practice related to ADHD and its treatment should concentrate on understanding both provider and family decision making when minority children exhibit ADHD symptoms. Developing policy and interventions to increase the acceptability and feasibility of stimulant medication or appropriate alternatives may be particularly important for non-Anglophonic families.

11.7.2. **ADHD interventions and policy framework appropriate to the Aboriginal population**

The lower exposure to stimulant use for ADHD in children and adolescents of Aboriginal parents in this thesis may simply reflect lower rates of ADHD diagnosis among them which could not be determined due to the limitation of the dataset as mentioned earlier in section 11.6.1. Either way, lower rates of diagnosis or stimulant use in Aboriginal children and adolescents suggests either Aboriginal parents do not perceive ADHD behaviour as a problem warranting treatment, have a negative attitude towards a western medicine approach to the condition, or their cultural competency provides a coping mechanism to construe the ADHD symptoms as a functional developmental stage. Alternatively, Aboriginal children who would stand to benefit from stimulant medication for ADHD may simply face barriers to access. Aboriginal children and adolescents should be protected from misdiagnosis and over-diagnosis. A better understanding of Aboriginal perceptions of ADHD and stimulant treatment is crucial to identify unmet needs and to develop targeted interventions that take into account the social factors and the impact of colonial practice on Aboriginal communities. Any ADHD intervention and policy framework must take into account a holistic approach to Aboriginal culture, beliefs and individual experience to provide the optimal care they need.
11.7.3. Training for health care professionals regarding cultural differences in understanding of ADHD and stimulant treatment

Cultural differences in understanding of and beliefs about ADHD and stimulant medication treatment have been discussed throughout the thesis. Individuals from different cultures perceive ADHD based on their cultural framework, which creates a unique cultural lens from which they construct their realities. It is important for health care professionals to assess parents and children with ADHD in the knowledge of their cultural interpretations. Formal training of health care professionals and health service providers on diverse cultures and their differences in perceptions about ADHD is recommended to increase cultural competence and thus to provide culturally appropriate services to families, to improve relationships with families and children, and finally to improve outcomes for both families and children living with ADHD.

11.7.4. Increasing sensitivity among health care professionals

As observed in Chapter 10, putting a child on stimulant medication is a difficult decision for parents to take. Parents take time and evaluate lots of considerations before they decide to accept a long-term scheduled drug for their child. Therefore, health care professionals and service providers need to be sensitive and respectful to parental decisions, and more supportive of parents through being available and willing to answer their queries, advising on the benefits of medications as well as possible side effects thereof, suggesting literatures available on the medication and, where desired, putting parents in touch with other parents in similar situations.

11.7.5. Development of regulation of stimulant use

The findings in Chapter 10 underline that an individual’s understanding of ADHD behaviour and their attitude towards stimulant treatment are important considerations for effective intervention and development of the regulation of stimulant treatment. Parents and individuals who do not perceive ADHD as an impairment to academic achievement may not want to consider stimulant treatment even when others consider it necessary; or may not desire an enhanced academic performance for fear the treatment may lead to non-medical stimulant use. As noted previously, some parents are cautious
about use of stimulant medications due to the possibility of long-term side effects, but administered it anyway, as they were concerned about their child’s diminishing self-esteem and perceived failure to be normal. More parents may consider stimulant medication if they perceive stimulants as less harmful, or if their expectations of normality increase.

11.7.6. Recognition of cultural influences on ADHD treatment as a health priority area

As a major and growing public health issue affecting all Western and European countries, the general awareness of the impact of ADHD diagnosis and stimulant medication use, and the degree to which the diagnosis and treatment disproportionately affects families, children and adolescents from different cultural and ethnic backgrounds in WA, needs to be increased. It is too simplistic to argue against the existence of ADHD in individuals from ethnic minorities on the basis of lower rates of stimulant medication use. Given the increasing rate of stimulant medication use in Australia, the number of ADHD diagnoses and utilisation of stimulant treatment in children and families from diverse cultural and linguistic background will undoubtedly increase in the near future; albeit many of them may not perceive ADHD as a medical condition. Cultural differences in the recognition of ADHD and thus the influences of culture on stimulant treatment must first be recognised and then designated a sufficient health priority for funding to be channelled into this area.

11.8. AREAS FOR FUTURE RESEARCH

11.8.1. Comparing stimulant medication use within the symptomatic population

As mentioned above as a limitation, due to an absence of data on anyone diagnosed with ADHD, but not ever treated with stimulant medication, in this thesis the use of stimulant use was compared between sociodemographic subgroups of the general population, who were the aggregate of people with and without ADHD symptoms. Therefore comparisons of stimulant medication use between different sociodemographic subgroups, but with the domain of the comparison restricted to those with ADHD symptoms might be a fruitful area for future research. At the very least, it would
remove a source of doubt about how best to interpret different rates of stimulant medication use across sociodemographic strata, such and those reported here.

11.8.2. Different risk factors

Acknowledging that cultural beliefs and perceptions are not the only explanations for the disparities in stimulant treatment between Anglophonic and non-Anglophonic people, this thesis recommends further research into the impact of financial hardship and spatial barriers due to residential remoteness on accessing stimulant treatment and ADHD-related services in ethnic minorities in Australia. Apart from cultural and sociodemographic factors, the disparities in stimulant treatment may also reflect clinician attitude servicing particular suburbs, type of clinician conducting diagnosis, teacher attitude, gender expectations of academic and career performance, and age relative to classmates. Future research exploring in greater depth in these areas would shed further light on the nature of any over-prescribing or under-prescribing of stimulant medications within certain subgroups within the population.

11.8.3. ADHD diagnosis and perception of ADHD in the Aboriginal population

There are grounds for exploring in greater detail the beliefs about ADHD and stimulant treatment held among members of Aboriginal communities and any barriers they perceive to gaining access to ADHD services. As outlined in chapter 6, the Aboriginal population in Australia generally remains the most socioeconomically disadvantaged cultural group in the country\(^{259,413-414}\), and in WA these citizens are concentrated in the rural or more remote parts of the State\(^{259,414}\). They experience ongoing racial discrimination\(^{265}\) and the aftermaths of colonial trauma\(^{314}\) and forced child removal\(^{264,315}\). The findings of the thesis suggest avenues for future more focussed research examining ADHD prevalence in Aboriginal children. First, a quantitative research endeavour should focus on comparing the rate of ADHD diagnosis and subsequent stimulant medication treatment for ADHD in the Aboriginal population of WA. Second, a quantitative research should undertake a thorough geographical investigation in exploring the differences between Aboriginal and non-Aboriginal prescribing rates, given that the higher relative proportion of Aboriginals are living in generally low prescribing country WA. Third, a qualitative study should be entertained to explore Aboriginal perceptions of ADHD and attitudes towards stimulant treatment
to increase our understanding of the cultural nuances of the disorder in Aboriginal people with an aim to help close the gap between health outcomes in non-Aboriginal and Aboriginal populations.

11.8.4. Different populations

Ideally a future qualitative research project should also include community members other than Anglophonic and Aboriginals to examine differences in the cultural understanding of ADHD and attitudes to stimulant medication treatment. Future study could also explore the diversity of perceptions and attitudes both within ethnic groups and across ethnic groups, and more geographically and socioeconomically representative communities. Additionally, using the insights of the explorative study in this thesis, further research could be conducted in a format such as an online survey, mail questionnaires or telephone survey that would measure the prevalence of these views in wider communities.

11.9. THESIS CONCLUSIONS

This thesis explored differentiating patterns in the use of stimulant medications for the treatment of ADHD in WA. Using data from i) the linked WA Birth Registrations, FCGS, MNS, MODDS; ii) HMDC, MODDS and Death Registrations; and iii) qualitative information collected through in-depth interviews, the following conclusions are made from the series of sub-studies presented in this thesis:

- Individuals or their parents born in traditionally non-Anglophonic countries were less likely to accept stimulant medication for ADHD treatment compared with their Anglophonic counterparts between 2003 and 2007.
- The mean age at onset of stimulant treatment for those with a non-Anglophonic background was 1-3 years older than in those with an Anglophonic background.
- Individuals with a father more so than a mother born in non-Anglophonic countries displayed a significant tendency to have reduced stimulant medication use, as well as to be older at the time of first stimulant medication treatment.
- Individuals being male, socioeconomically disadvantaged and living in the metropolitan area were associated with higher stimulant medication use.
• The use of stimulant medication for ADHD treatment was significantly lower in children and adolescents of Aboriginal parents compared with that of Australian born non-Aboriginal parents.
• Aboriginal mothers more so than fathers were associated with lower stimulant medication use in their children and adolescents.
• In general, participants with Anglophonic background living in the Perth metropolitan areas had an understanding of ADHD behaviour as a medical condition and perceived ADHD as creating an impairment to one’s academic and vocational success in life. Consequently, respondents accepted stimulant medications as an effective treatment choice to improve ADHD behaviour.

The findings from this thesis are consistent with and are an addition to the findings of studies in other developed countries, with the combined evidence having implications for health policy and practice. The major strengths of this thesis lie in the triangulation of quantitative and qualitative study design and a large sample size using linked data. Willingness to prefer stimulant medication treatment for ADHD behaviours is a pivotal sociocultural question that needs to be considered in developing interventions, policies and programs related to ADHD to provide appropriate services and to achieve better life course outcomes.
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APPENDIX I
Conference Abstract

1st Asian Congress on ADHD 2012
Kim Koo Museum and Library Seoul, Korea

Does parental country of birth play a role in pharmacotherapy for Attention Deficit Hyperactivity Disorder (ADHD)? A Whole-Population Linked Data Study

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1School of Population Health, The University of Western Australia, AUSTRALIA

Aim: The aim of this study was to determine whether parental country of birth impacts on the use of stimulant medications (SM) for the treatment of ADHD in Western Australia (WA).

Methods: A retrospective cohort of children and adolescents born in WA from 1980 to 2007 was linked to prescriptions of SM for ADHD between 2003 and 2007, identified through the statutory Stimulant Notification Database and Stimulant Dispensing Database maintained by the WA Department of Health. Each parent’s race and country of birth was ascertained using a genealogical linkage system based on birth, midwives, death and hospital records. Using de-identified linked records and logistic regression, we examined the association between dispensed SM for ADHD and parental country of birth.

Results: Among 692,761 people born in WA between 1980 and 2007, 13,803 (2%) were dispensed SM for ADHD. Of these, 734 (5.3%) had parents born in Africa, Asia, the Middle East or South American countries. Most children (12,951, 88.8%) had parents born in Australia, North America and Europe. Adjusted results showed a significant association between parental country of birth and the dispensed SM. Children who had parents born in traditionally non-English speaking countries such as Africa, Asia, the Middle Eastern or South America were less likely to be treated with SM (OR=0.55, 95%CI 0.34-0.87) compared with children of parents born in Australia, North America and Europe. Socio-economic disadvantage and residential remoteness were also significant predictors for a decreased likelihood of using SM to treat ADHD.

Conclusion: Our findings that parental country of birth is associated with a reduced SM use by children for ADHD highlights the importance of identifying factors underlying cultural differences in SM prescribing patterns for the treatment of ADHD. Such results could shed light on the likelihood of over-prescribing or under-prescribing of SM within certain cultural groups as well as possible avenues for alternative therapeutic approaches.
Explaning Ethnic Differences in the Use of Stimulant Medications for ADHD: A Whole-Population Study

Manonita Ghosh*, D’Arcy Holman, David Preen

Aim

To explain ethnic differences in the use of stimulant medications among Western Australian (WA) children and adolescents.

Methods

WA Linked Datasets

- Stimulant Notification and Dispense to identify children and adolescents who had records of stimulant usage for ADHD from 2003-2007.
- Midwives Register to identify parental country of birth.

The Study Cohort

- Among 692,761 people, 13,803 had dispensed stimulant for ADHD. Of these, 40 had parents born in Africa, Asia, Middle East or South America, while 12,961 had parents born in Australia, Europe or North America.

Data Analysis

- Data were analyzed using logistic regression and univariate analysis to examine the differences in stimulant usage for ADHD by parental country of birth, age, socioeconomic status and geographical remoteness.

Results

- Children and adolescents who had parents born in non-English speaking countries were less likely to be treated with stimulant compared to those who had parents born in Australia, Europe or North America.
- Children and adolescents with parents born in non-English speaking countries tended to delay in stimulant usage.
- Father’s country of birth was an influential predictor for a decreased likelihood of using stimulant.
- The Socio-economic disadvantage and Geographical Remoteness were associated with stimulant usage.

Table 1: Odds Ratios for stimulant medications

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Crude OR (95% CI)</th>
<th>Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>LPNO? parents</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One parent born in LPNO</td>
<td>0.59 (0.41-0.84)</td>
<td>0.59 (0.42-0.84)</td>
</tr>
<tr>
<td>Both parents born in LPNO</td>
<td>0.52 (0.27-1.01)</td>
<td>0.49 (0.25-0.95)</td>
</tr>
<tr>
<td>Mother’s age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.00 (0.92-1.14)</td>
<td>1.00 (0.90-1.14)</td>
<td></td>
</tr>
<tr>
<td>Mother’s age by Log mother’s age</td>
<td>0.99 (0.97-1.01)</td>
<td>0.99 (0.97-1.03)</td>
</tr>
<tr>
<td>Residential Remoteness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural Western Australia</td>
<td>0.83 (0.73-0.94)</td>
<td>0.83 (0.78-0.86)</td>
</tr>
<tr>
<td>Remote Western Australia</td>
<td>0.61 (0.54-0.70)</td>
<td>0.62 (0.57-0.68)</td>
</tr>
<tr>
<td>Missing</td>
<td>0.89 (0.83-0.95)</td>
<td>0.89 (0.81-0.97)</td>
</tr>
</tbody>
</table>

Socioeconomic disadvantaged:
- Less disadvantaged: 1.06 (1.01-1.11)
- Little disadvantaged: 1.18 (1.11-1.26)
- More disadvantaged: 1.15 (1.09-1.21)
- Most disadvantaged: 1.39 (1.31-1.47)
- Missing: 1.09  (0.95-1.25)

Dependent variable - any stimulant usage for ADHD.

Table 2: Mean age for children used stimulants

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Mean age</th>
<th>Mean difference (25%)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>LPNO? parents</td>
<td>11.28</td>
<td>0.04 (0.06-0.80)</td>
<td>0.24</td>
</tr>
<tr>
<td>Father’s age</td>
<td>11.68</td>
<td>0.04 (0.06-0.80)</td>
<td>0.24</td>
</tr>
<tr>
<td>Residential Remoteness</td>
<td>11.25</td>
<td>0.16 (0.04-0.80)</td>
<td>0.01</td>
</tr>
<tr>
<td>Socioeconomic disadvantaged</td>
<td>11.46</td>
<td>0.06 (0.06-0.80)</td>
<td>0.01</td>
</tr>
</tbody>
</table>

Conclusions

- It is important to identify factors underlying ethnic disparities in the use of stimulant medications for ADHD treatment.
- Improving knowledge of cultural aspects within certain ethnic groups may better facilitate the diagnosis of ADHD.
- Understanding cultural differences may improve the relationship between patients and clinicians, and provide avenues for alternative therapeutic approaches.

Acknowledgements: University of Western Australia, and Data Linkage Branch, Department of Health WA.
APPENDIX III
Notification of Treatment with Stimulant Medication

Notification of treatment with stimulant medication

1. Patient details
   - Forename: ____________________________  Surname: ____________________________
   - Address: ____________________________  Postcode: ____________________________
   - DOB: /  /  Medicare no: ________  Gender:  M  F
   - Weight (kg) (children only): ________

2. Notification type
   - Notification: □   □   □   □   □   □   □   □   □   □   □   □
     - Reason: ________  Player moved: ________  Patient moved: ________
     - Comorbidity: ________  Patient moved: ________  Drug side effects: ________
     - Substance abuse: ________  Dose: ________  Non-standard condition: ________
   - Subsequent: ________  Prescriber moved/retired: ________  Other: ________
   - Other: ________

3. Primary condition being treated
   - ADHD  > If ADHD is primary condition: ____________
     - Which diagnostic criteria were used? ________
   - Other: ________
     - ODD: ________
   - CD: ________
   - Other: ________

4. Stimulants to be prescribed and total daily dose
   - Dexamphetamine: ________ mg/day
   - Add: ________ mg/day
   - Methylamphetamine: ________ mg/day
   - Add: ________ mg/day

5. Authorised stimulant prescriber
   - Forename(s): ____________________________  Surname: ____________________________
   - SPN: ________  Is the patient being treated at a Registered Public Clinic?  Yes  No
   - If yes, please specify: ____________________________
   - Address: ____________________________  Postcode: ____________________________

6. Co-prescriber
   - Nominated co-prescriber only: ________  All practitioners at the same practice as nominated co-prescriber: ________
     - Forename(s): ____________________________  Surname: ____________________________
     - Practice: ____________________________
   - SPN holder is required to provide a copy of the notification to the nominated co-prescriber

7. Acknowledgement
   - Medical practitioner
     - I confirm that I have made the patient(s)/guardian aware that the information included on this form will be forwarded to the Department of Health (WA) to meet legislative requirements and that de-identified data may be used for the purpose of authorised research. I also hereby notify the Chief Medical Officer (CMO) of Health that the above patient will be treated in accordance with the Stimulant Preparing Code and in accordance with a written authority from the CEO if required.
     - Signature: ____________________________  Date: ____________________________

Pharmaceutical Services Branch  PO Box 8172, Perth Business Centre WA 6849  Fax 9222 2463  Phone 9222 6883

Delivering a Healthy WA
# APPENDIX IV

Hospital Inpatient Summary Form

<table>
<thead>
<tr>
<th>Account/Adm. No.</th>
<th>Episode of Care</th>
<th>Client Identifier (CBS)</th>
<th>Client's Address</th>
<th>Date of Admission Time/Date</th>
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</thead>
<tbody>
<tr>
<td></td>
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</tbody>
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<table>
<thead>
<tr>
<th>Hospital Establishment</th>
<th>Statement</th>
<th>First Name</th>
<th>Second Name</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Residential Address (No. Street)</th>
<th>Postcode</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>State/Territory of Residence</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>R.O.B.</th>
<th>Sex</th>
<th>Indigenous Status</th>
<th>Marital Status</th>
<th>Employment Status</th>
<th>Interpreter Service</th>
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</thead>
</table>

<table>
<thead>
<tr>
<th></th>
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<table>
<thead>
<tr>
<th>Mode of Separation</th>
<th>Discharged To</th>
<th>Diagnosis of Illness</th>
<th>Cause of Death</th>
<th>Clinical On Separation (MDCC)</th>
<th>Clinical On Separation (MDCC)</th>
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<tbody>
<tr>
<td></td>
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</table>

## CLINICAL DETAILS

<table>
<thead>
<tr>
<th>Diagnosis (Using Australian Coding Standards)</th>
<th>Cond. Occurrence Flag</th>
<th>Cond. Occurrence Code</th>
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<tr>
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</table>

<table>
<thead>
<tr>
<th>Principal Diagnosis</th>
<th>Additional Diagnosis</th>
<th>ICD-10-AM Code</th>
<th>CRF Code</th>
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</thead>
<tbody>
<tr>
<td></td>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>Principal Procedure</th>
<th>Doctor's Name</th>
<th>Enter ID</th>
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<td></td>
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</table>

## Performance Activity & Quality

<table>
<thead>
<tr>
<th></th>
<th>ICD-10-AM Code</th>
<th>CRF Code</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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</table>
### APPENDIX V

**Additional Table**

Mean age in years at initial prescription in those receiving a stimulant medication for ADHD according to racial and demographic factors

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Univariate Analysis</th>
<th></th>
<th>Mean age</th>
<th>Mean difference (95% CI)</th>
<th>p-value</th>
<th>Multivariate Analysis</th>
<th>Mean age</th>
<th>Mean difference (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Aboriginal</td>
<td>8.72</td>
<td>1.0</td>
<td>8.69</td>
<td>-0.14 (-0.60, 0.32)</td>
<td>0.55</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Both parents Aboriginal</td>
<td>8.63</td>
<td>-0.09</td>
<td>8.55</td>
<td>-0.35 (-0.82, 0.11)</td>
<td>0.14</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Only father Aboriginal</td>
<td>8.33</td>
<td>-0.39</td>
<td>8.33</td>
<td>-0.43 (-1.00, 0.14)</td>
<td>0.14</td>
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<td></td>
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<tr>
<td>Only mother Aboriginal</td>
<td>8.24</td>
<td>-0.48</td>
<td>8.26</td>
<td>-0.14 (-0.60, 0.32)</td>
<td>0.55</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8.70</td>
<td>1.0</td>
<td>8.47</td>
<td>-0.02 (-0.20, 0.17)</td>
<td>0.86</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Female</td>
<td>8.69</td>
<td>-0.01</td>
<td>8.45</td>
<td>-0.06 (-0.25, 0.12)</td>
<td>0.50</td>
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<tr>
<td>Geographical remoteness</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>8.68</td>
<td>1.0</td>
<td>8.53</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Rural</td>
<td>8.60</td>
<td>-0.08</td>
<td>8.47</td>
<td>-0.06 (-0.25, 0.12)</td>
<td>0.50</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Remote</td>
<td>8.97</td>
<td>0.29</td>
<td>8.84</td>
<td>0.30 (-0.05, 0.66)</td>
<td>0.09</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socioeconomic disadvantaged</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Least disadvantaged</td>
<td>8.74</td>
<td>1.0</td>
<td>8.44</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Less disadvantaged</td>
<td>8.72</td>
<td>-0.03</td>
<td>8.42</td>
<td>-0.02 (-0.22, 0.18)</td>
<td>0.84</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Little disadvantaged</td>
<td>8.51</td>
<td>-0.24</td>
<td>8.24</td>
<td>-0.20 (-0.46, 0.05)</td>
<td>0.12</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More disadvantaged</td>
<td>8.39</td>
<td>-0.36</td>
<td>8.12</td>
<td>-0.33 (-0.68, 0.03)</td>
<td>0.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Most disadvantaged</td>
<td>8.62</td>
<td>-0.13</td>
<td>8.36</td>
<td>-0.09 (-0.33, 0.15)</td>
<td>0.47</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX VI
Flyer for LPNO Participants

What do you think about ADHD?
Do you wonder how your experience differs from others?
Do you want to share your opinion about ADHD?

Help us find out cultural differences in the notion of ADHD

Who we are:
This is a PhD research project, in the School of Population Health, University of Western Australia

What to find:
The influence of cultural differences on the treatment of ADHD

Who can participate:
- Adult born in Africa, Asia, Middle East or South America and diagnosed with ADHD
- Parents born in Africa, Asia, Middle East or South America and have children diagnosed with ADHD

What to expect:
You will participate in an interview for up to one hour to discuss issues such as your perceptions, beliefs and attitudes about ADHD.

Your information is confidential and non-judgmental.

Chief investigator: Winthrop
Professor D'Arcy Holman

If you are interested please call
Manoella Ghosh on 0423498365
APPENDIX VII
Information Letter

Project Title: Cultural influences on the treatment of Attention Deficit Hyperactivity Disorder (ADHD) in the Western Australian community

The above research project is being undertaken by Ms. Manonita Ghosh, Manonita.Ghosh@uwa.edu.au who is studying towards her PhD at The University of Western Australia where she is supported by an Australian Postgraduate Scholarship.

Attention Deficit Hyperactivity Disorder (ADHD) has been a topic of intense scientific research in the past two decades. Despite the large volume of research dedicated to ADHD, the influence of cultural differences on the treatment of the condition is still to be adequately addressed. Parents’ cultural background and the attitude of society towards acceptable behaviours may influence the treatment.

The main objective of the research is to find out how different cultural understandings of human behaviour might lead to different perspectives on ADHD and how best to deal with it. In particular, the research aims to investigate the effects of parental country of birth and race, as well as a person’s own country of birth and nominated race, on the use of medication for the treatment of ADHD in Western Australia.

If you are currently or at any time in your life were diagnosed as having ADHD, this letter invites you to participate in this project. Parents of children with diagnosed ADHD are also invited to participate. You will be asked to participate in an interview for up to one hour to discuss issues such as your perceptions, beliefs and attitudes towards ADHD.

All information you provide during the interview will be completely confidential. At no time will your identity be disclosed in any published results from this study. Your involvement in this study is voluntary and you can withdraw at any time without reason and prejudice. Should you require, this project will offer you an experienced psychologist or a counsellor to talk through any issues. Your participation in this study does not prejudice any right to compensation, which you may have under statute or common law. Your assistance with the research would be highly appreciated.
APPENDIX VIII
Participant Consent Form

Project Title: Cultural influences on the treatment of ADHD in the Western Australian community
Researchers: Manonita Ghosh, Prof D’Arcy Holman, Prof David Preen,
Email: manonita.ghosh@uwa.edu.au; darcy.holman@uwa.edu.au; david.preen@uwa.edu.au

This research aims to investigate the effect of parental country of birth and race, as well as a person’s own country of birth and nominated race, on the use of medication for the treatment of Attention Deficiency Hyperactivity Disorder (ADHD) in Western Australia. This research will identify factors that affect a person’s perceptions and attitudes towards ADHD, which may lead people to seek treatment. The interview will take about an hour to discuss issues such as your perceptions, beliefs or attitudes about ADHD. Information provided in the interview will be held in strict confidence. At no time will your identity be disclosed on published results from this study. Interview conversations will be recorded for research purposes only and recordings will be kept in a locked and secure cabinet, and then destroyed five years after the research is complete. Please inform the researcher if you do not want your interview recorded, or want to stop the recording at any time during the interview. Your involvement in this study is voluntary and you can pull out at any time.

As a part of this study you will also be asked to fill in a questionnaire, which will take approximately 5 minutes. You do not have to answer any question that you do not want to answer. Further, you may choose not to complete this questionnaire at all.

I ………………………………………………… (your full name) have read the information above and any questions have been answered to my satisfaction. I agree to participate in this activity, realising that I may pull out at any time without giving a reason and without consequence. I understand that all information provided is treated as strictly confidential and will not be released by the researcher unless required to do so by law. I agree that research data gathered for the study may be published, provided my name or other identifying information is not used.

Signature of participant

Signature of the researcher

Date-------------- Date-------------

The Human Research Ethics Committee at The University of Western Australia requires that all participants are informed that, if they have any complaint regarding the manner, in which the research project is conducted, they can contact the lead researcher (D’Arcy Holman <dholman@meddent.uwa.edu.au>) or, alternatively, the Secretary, Committee for Human Research Ethics Committee, Registrar’s Office, UWA, Nedlands, 6907 (telephone no. 6488 3703).
APPENDIX IX
Interview Guide

1. What was your experience, physically and emotionally when this issue began?
2. What made you seek professional help?
3. How was the decision made to see a psychiatrist or a pediatrician?
4. What was the procedure to see the psychiatrist or pediatrician?
5. What do you think about ADHD?
6. How did you feel being/your child being diagnosed with ADHD?
7. How did you feel being/your child being prescribed a medication for ADHD?
8. How was the decision made to consume medication for you/your child?
9. Did you want to take the medication and why or why not?
10. What is your experience after taking medication?
11. What is your experience about the medication doses?
12. What is your experience of the costs involved in seeing the doctor and obtaining medications?
13. How do you feel being a parent?
14. How do you perceive what other people think about you?
15. How do you want them to see you?
16. Who do you think is responsible for this condition (ADHD)? Why? How?
17. How do you compare your life to your friend’s life?
18. Where do you get most advice from - family, professional, friends or someone else?
19. How do you deal with the reality? How do you cope with your feelings?
20. Do you think you/your child has an illness or a mental health issue?
21. How do you think the medication may help you for this condition?
22. How do you think people from different culture see ADHD?
23. How do you compare your life in Perth to your life in your home country?
24. Do you think your experience would be same or different if you were in your home country?
25. How do you think people in your home country see ADHD?
26. Do you have any other comments you want to add?
27. What is your ethnic background?
28. Do you think that your ethnic background influence the way you think about ADHD?
29. Do you think that your social background or whether you live in a city or a rural area influences the way you think about ADHD?
30. Do you have any other comments?
APPENDIX X
Demographic Questionnaire

1. Date questionnaire completed________________
2. Your age __________________________
3. Your child/ren’s age(s) __________________________
4. Number of children __________________________
5. Your occupation __________________________
6. Name of your suburb __________________________
7. Marital status: (circle your answers)
   Single married never married remarried
   divorced widowed de-facto
8. Are you involved in any community work? e.g. sports, cultural program Y/N
9. If yes, what do you do? __________________________
10. Is your child involved in any activities? e.g. sports, cultural program Y/N
11. If yes, what does she/he do? __________________________
12. What is your partner’s occupation? __________________________
13. What is your country of origin? __________________________
14. What is your ethnic identity? __________________________
15. What languages do you speak? __________________________
16. How long have you been in Australia? __________________________
17. Are you an Australia citizen? Y/N
18. If no, what is your resident status in Australia?
   Permanent resident temporary resident visitor other ________
19. What visa category did you have when you came to Australia?
   Permanent resident spouse family reunion Refugee other ________
20. Did you want to come to Australia? Y/N
21. Do you want to stay in Australia? Y/N
22. How many of your family live with you in your house? ________
23. How many of your family live nearby? __________________________
24. Where do they live? (tick your answers)
   Next door next street same neighbourhood next suburb other ________
25. Do you have any relatives or friends who help you? Y/N
26. What kind of help do they give?
   Financial emotional house work other ________
27. Have you ever been diagnosed with ADHD? Y/N
28. If yes, at what age were you diagnosed with ADHD? ________
29. Have any of your children been diagnosed with ADHD? Y/N
30. If yes, how many of your children have been diagnosed with ADHD? ________
31. At what age were your children diagnosed with ADHD? ________
32. Do you have any other family member diagnosed with ADHD? Y/N/Not sure
33. If yes, how many of your family member is diagnosed with ADHD? ________
34. If yes, what is the relationship with you? ________
35. At what age were they diagnosed with ADHD? ________
36. Did you take any prescribed medication for ADHD? Y/N
37. Did your child take any prescribed medication for ADHD? Y/N
38. At what age did you take your first medication? ________
39. At what age did your child take first medication? ________
40. What medication were you prescribed? __________________
41. What medication was your child prescribed?__________________
42. How long have you been taking medication? _________________
43. How long has your child been taking medication? ______________
44. Do you/your child use any alternative treatment for ADHD? Y/N
45. If yes, what treatments do you/your child use?________________

Thank you for your participation
APPENDIX XI
Exploring Parental Country of Birth Differences in the Use of Psychostimulant Medications for ADHD: a Whole-Population Linked Data Study

EARLY HEALTH INDICATORS

Exploring parental country of birth differences in the use of psychostimulant medications for ADHD: a whole-population linked data study

Manonita Ghosh,1 C. D'Arcy J. Holman,1 David B. Preen1

Stimulants are the most widely prescribed medication in children and adolescents for the treatment of attention deficit hyperactivity disorder (ADHD). Their use has been steadily increasing in developed countries like the US and Australia.1,2 There is evidence suggesting the efficacy and cost-effectiveness of stimulants in the management of ADHD.3,4 However, concerns have been raised about the risk of long-term stimulant dependence, their use for inappropriate reasons, and the safety of exposure to these medications in developing children, including possible cardiovascular complications.5,6

The past two decades have seen large variations in dispensed prescriptions of stimulant medication in Western Australia (WA). From 1989 to 2000, 85-90% of the 20,649 Western Australians on prescription stimulants were children.7 The proportion of children on stimulant medication peaked in 2002 at 2.6% per capita,8 before it declined by one-third between 2006 and 2010, following the inception of the Statutory Stimulant Regulatory Scheme in mid-2009 pertaining to all prescribing of these medications in the state.9 In 2011, there were 15,955 patients receiving prescribed stimulants: 39% of them were children – an increase of 6% from 2010.9

These temporal variations have engendered considerable controversy among some policy makers and clinicians about potential over- or under-prescription of stimulant medication for children with ADHD.10 In addition, regional prescribing variations and higher rates of stimulant medication use for treatment of ADHD in lower socioeconomic areas in WA have been reported.11

Abstract

Objective: To explore parental country of birth differences in the use of stimulants for attention deficit hyperactivity disorder (ADHD) in Western Australian (WA) children and adolescents.

Methods: Statutory WA stimulant notification and dispensing records from 2003 to 2007 were linked to whole-population state data from 1989 to 2007. Parental attributes were obtained through the WA Family Connections genealogical linkage system. Using multivariable logistic and linear regression, differences in WA stimulant use for ADHD by parental country of birth, socioeconomic status and geographical remoteness were examined.

Results: Of 671,231 people born in WA between 1989 and 2007, 13,355 (2%) used stimulants for ADHD. Of these, 7,274 (9%) had parents born in Africa, Asia, the Middle East or South America, and 12,606 (19%) had parents born in Australia, North America and Europe. Children and adolescents with parents born in traditionally non-Anglophonic countries were less likely to be treated with stimulants (OR=1.7, 95%CI 1.4-2.1) than those with parents born in Anglophonic countries. Socioeconomic advantage and residential remoteness were also significant independent predictors of a decreased likelihood of stimulant use.

Conclusions: The results highlight the importance of improving knowledge about cultural differences in access to and attitudes towards the diagnosis of ADHD and different approaches to its treatment.

Key words: ADHD, country of birth, linked data, stimulant medication

Despite the polarisation of opinion regarding the prescribing patterns over time, little or no attention has been paid to the diagnostic and treatment of the condition in children with different racial and ethnic backgrounds in Australia. In the US, the occurrence and treatment of the condition has been found to vary with insurance status,12 family structure13 and geographic and demographic factors,14 yet we know little about the possibility of such variations in Australia, where there is stronger policy support for universal access to healthcare.

Culture can influence parents’ understanding and interpretation of child behaviour and development.14 Parents’ interpretation of child behaviour may influence clinical decisions, because reports from parents are commonly used in the comprehensive assessment leading to an ADHD diagnosis.15 Consequently, it is important to determine variations in the prescribing of stimulant medication within different sections of the population, including different ethnic groups.

This study explores disparities in the use of stimulant medication for the treatment of ADHD in WA across parental country of birth and other socio-demographic factors.

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Submitted: January 2014; Revision requested April 2014; Accepted: June 2014

The authors have stated they have no conflict of interest.

Australian and New Zealand Journal of Public Health
© 2014 Public Health Association of Australia
2015 vol. 39 no. 1

88
Methods

Data sources
We used de-identified whole-population linked data that are routinely collected and maintained by WA Department of Health (DoH). A retrospective cohort of children, adolescents and young adults born in WA from 1980 to 2007, and identified from registered birth certificates, was linked to the prescription of stimulant medication dispensed for ADHD only between 2003 and 2007, identified from statutory stimulant notification and stimulant dispensing records maintained by the DoH. Birth registrations were used to define parent-child relationships as well as to determine each parent’s country of birth. Midwife records were also linked to birth registration to verify the relationships between mothers and children. Moreover, mother’s age on the date of delivery was ascertained from the midwife records because the birth registrations captured mother’s age at the time the birth was registered.

Scores for residential and socioeconomic disadvantage were derived from the Accessibility/Remoteness Index of Australia (ARIA), and the Index of Relative Socio-Economic Disadvantage (IRSD) using mother’s address recorded on the midwife forms. ARIA scores were grouped into three levels: metropolitan, rural and remote. The IRSD provides an area-based measure of social disadvantage for each person in the data. This metric is allocated based on Collection Districts of 220 households and is used as a means to control for socioeconomic status. IRSD scores were grouped into five levels of socioeconomic disadvantage: least disadvantaged (75% of the population), less disadvantaged (50–74%), little disadvantaged (25–49%), more disadvantaged (10–24%) and most disadvantaged (less than 10%).

Analytic approach
Parental country of birth was classified according to the Human Relations Area Files known as HRAF World Cultures, an anthropological database that contains information on aspects of cultural and social life, and classifies cultures into eight major geographical regions: Asia, Europe, Africa, North America, the Middle East, Oceania (including Australia and New Zealand), Central America and the Caribbean, and South America. We combined Central America and the Caribbean and South America into one category, referred to as South America. Because the majority of parents were born in Australia, which according to the HRAF fell under Oceania, we referred to this category as Australia and New Zealand.

We further aggregated parental country of birth into lower propensity national origin (LPPNO) and higher propensity national origin (HPNO) countries, based on a preliminary analysis that examined other national groupings of sub-regions (such as Central Africa, Northern Africa, Southern Africa, Western Africa, etc.) classified by the HRAF database. Our preliminary results showed a tendency for reduced stimulant use for ADHD in individuals with parents born in the LPPNO countries, compared with individuals with parents born in Australia or New Zealand, Europe or North America (the HPNO countries). Thereafter, we relied on a comparison between parental countries of birth based on the LPPNO/HPNO status of each mother and father. The numbers were too low for a less aggregated analysis at the individual’s parent level.

Statistical analysis
We measured the use of stimulant medication using the binary outcome of having at least one record of stimulant prescription dispensed at any time between 2003 and 2007. Crude and multivariate logistic regression models were used with adjusted models controlling for a range of socio-demographic and clinical characteristics to examine factors associated with stimulant medication use for the treatment of ADHD in the entire birth cohort. Adjustment for mother’s age as a continuous covariate was performed using a Box-Tidwell transformation. Multiple linear regression was used to compare unadjusted and adjusted mean ages in the individuals who were prescribed a stimulant medication for the first time.

Parents who identified themselves as Aboriginal, Torres Strait Islander and/or Pacific Islanders were excluded from our analysis. However, due to small relative numbers, the results were essentially the same (OR=0.55, 95% CI 0.34–0.87) when Indigenous parents were included. Even though the Indigenous parents were born in Australia, their perception of mental or behavioural disorder could be different from the perception of non-Indigenous Australian parents. It is beyond the scope of this article to discuss Indigenous attitudes and beliefs about ADHD.

Ethics approval
The study was approved by the Human Research Ethics Committee of the University of WA and the WA DoH Human Research Ethics Committee.

Results

Observed differences in stimulant use
A total of 13,535 (3.0%) children and adolescents of the 571,231 cohort who were born in WA in 1980–2007 were prescribed stimulant medication for ADHD treatment between 2003 and 2007. The characteristics of the study participants are shown in Table 1. The mean age at first stimulant use was 13 years (SD=5 years). More than half (n=6910, 51%) were children aged 5–12 years, and 1% (n=173) were children less than 4 years old (data not shown), and 77% were male. The majority of the ADHD individuals (88.6%) had HPNO parents born in Australia, Europe or North America while a much smaller proportion (5.4%) had one or both HPNO parents born in Africa, Asia, the Middle East or South America. More than 62% lived in the metropolitan area, 15% in rural and 8% in remote areas. More than two-fifths of the individuals (41%) came from the least socioeconomic disadvantaged group. More than one-fifth (21%) were classified as less disadvantaged, nearly 10% (7%) were disadvantaged, about 1% more disadvantaged, and 1% were in the most disadvantaged group, while 12% had information unknown.

Differences in the effects of parental country of birth and family characteristics on stimulant use
Crude and adjusted odds ratios pertaining to stimulant medication use obtained from logistic regression for the LPPNO status of the individual’s mother and father, and each residential remoteness and socioeconomic disadvantage category are shown in Table 2. Results for the adjusted model were similar to the crude results and indicated that individuals with two HPNO parents had 89% lower odds (OR=0.17, 95% CI 0.14–0.21) of having been prescribed stimulants, compared to individuals with two HPNO parents. Individuals with an HPNO father had 47% lower odds (OR=0.53, 95% CI 0.47–0.61), while individuals with an LPNO mother had 10% lower odds (OR=0.90, 95% CI 0.72–1.10), compared to individuals with two HPNO parents. Individuals born to mothers in rural and remote areas were significantly less likely
to be exposed to stimulant medication compared with metropolitan residents, with greater reductions in the likelihood of stimulant medication treatment as remoteness category increased (Table 2). Those from the little, more and most disadvantaged areas had significantly increased odds of stimulant medication use compared with their less disadvantaged counterparts.

The mean age of initial treatment with stimulant medication for those with an LPMO father was almost one year older than those with an HPNO father (13.31 vs. 12.48 years after adjustment, p<0.001; Table 3). Although individuals with an LPMO mother also tended to be older at first use of stimulant medication, this difference was less marked. Individuals from the least disadvantaged socioeconomic areas were between 1.36 and 0.93 years older at the time of first use of stimulant medication compared with more disadvantaged individuals whereas there was an inconsistent pattern of results for age at first use according to residential remoteness.

Discussion

Our results show that individuals who had parents born in traditionally non-Anthropophic, non-European regions such as Africa, Asia, the Middle East or South America were significantly less likely to be treated with stimulant medication compared with those whose parents were born in Australia, Europe or North America. This association was stronger when the father was born in an LPMO country than when the mother was. ADHD individuals with an LPMO father also displayed a significant tendency to be older at the time of first stimulant use.

These findings of cultural disparities in stimulant use are consistent with another study, and could be explained by cultural differences in the expectation, diagnosis and treatment of behaviour associated with ADHD. O’Mahony and Donnelly emphasised the cultural norms and health attitudes that immigrants bring with them from their homelands, stressing that culture shapes immigrants’ responses to health and illness and provides a coping mechanism for mental health. Subsequently, culture plays a key role in determining how parents internalise and respond to their child’s behaviour, and in their beliefs about appropriate medication for behaviour problems. Parents perceive their child’s behaviour based on their own cultural upbringing, their attitudes about behavioural problems and their beliefs about appropriateness and effectiveness of pharmacotherapy.

Parents in Confucian culture are expected to take personal responsibility for their child’s behaviour and this may induce reservations about the use of medication. African-American parents have a socially constructed view of ADHD and are less likely to view a child’s behaviour as pathological. Similarly, African-American parents were found to exhibit reduced faith in medical professionals and a generally negative perception of ADHD treatment with medication, which in one study apparently acted as a barrier to using ADHD treatment services. Similarly, Iranian parents were reported to not consider the behaviour associated with ADHD.
symptoms as pathologic, but instead to regard these behaviors as "mischievous acts" or a "natural behavioral stage of childhood development." The researchers in that instance noted that parents' fear of embarrassment with the stigma of mental illness and psychiatric treatment were reasons for delaying treatment in Iranian culture. Similarly, Latino parents feared a stigma attached to medication use for ADHD and as a result delayed its treatment, while Indian parents were reluctant to accept what they perceived as a psychiatric label for their children's behavior and were more likely to pursue non-pharmacological approaches such as behavior management, educational and religious treatments, instead of stimulant medication.

There is some evidence to suggest that mothers tend to rate levels of ADHD symptoms as more serious than fathers, and also that fathers are more likely to perceive their children as having more ADHD symptoms than mothers. This tendency is not limited to the United States and European countries, as a recent study found a similar pattern in Japan. The researchers suggested that cultural factors, such as gender roles and expectations, may play a role in how parents perceive and respond to ADHD symptoms in their children.

Use of psychostimulant medications for ADHD

<table>
<thead>
<tr>
<th>Table 3: Comparing patients' mean age at first stimulant use</th>
<th>Unadjusted</th>
<th>Adjusted</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean age (yr)</td>
<td>Mean difference in yr (% difference)</td>
</tr>
<tr>
<td>ADHD</td>
<td>12.73</td>
<td>0.73 (1.40)</td>
</tr>
<tr>
<td>ADHD</td>
<td>12.86</td>
<td>0.73 (1.26)</td>
</tr>
<tr>
<td>ADHD</td>
<td>12.79</td>
<td>0.73 (1.24)</td>
</tr>
<tr>
<td>ADHD</td>
<td>12.62</td>
<td>0.73 (1.18)</td>
</tr>
<tr>
<td>ADHD</td>
<td>12.68</td>
<td>0.73 (1.17)</td>
</tr>
</tbody>
</table>

Limitations
While the results of this analysis are consistent with the findings from a number of previous studies, some limitations must be considered.

First, ethnicity information could not be obtained. Therefore, we relied on parental country of birth information recorded on birth and midwife records for parental ethnic identity. Although country of birth may be expected to influence people's perceptions and beliefs, it is possible that in some instances reliance on the country of birth information masked people's true ethnic identity. For instance, some parents who were...

2015 vols. 39 no. 1
Australian and New Zealand Journal of Public Health
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born in South Africa, and thus classified as LPNO in this study, may have better fitted in the HPNO classification, due to their European ethnic background. These limitations in the measurement of parental ethnic identity may have influenced the findings of the analysis. Second, some LPNO parents were likely to have been newly arrived migrants to Australia, and may have faced a number of challenges in accessing healthcare due to a lack of knowledge about available services, linguistic barriers and financial difficulties, compared with LPNO parents who have lived in Australia for some time. However, due to the absence of data, we were not able to evaluate parents' length of stay in Australia. It is possible that the additional challenges for the new migrants created a barrier to accessing ADHD services and thus may have influenced the results. In spite of that, we suspect that it is the culturally embedded values and expectation of behaviours that mostly determines LPNO parents' help-seeking and access to care for ADHD. In a cross-cultural study, immigrants are noted to be governed by their own cultural attitudes towards health and healthcare regardless of length of stay in a host country. Finally, we are confident about the generalisability of our analytic findings on associations between stimulant medication use, Australia-wide, that the GP population is representative of Australia as a whole. However, it should be noted that the use of stimulant treatment across Australia varies and so purely descriptive results, such as the 2% birth cohort exposure, may vary between Australian jurisdictions.

**Conclusion**

Children or adolescents who had parents born in Africa, Asia, Middle East or South American countries were less likely to use stimulant medication for the treatment of ADHD compared to those with parents born in Australia, New Zealand, Europe or North America. Father’s birthplace seemed to be particularly influential in reducing and delaying stimulant use in people from traditionally non-European countries. We also observed differences in stimulant use across socioeconomic groups and remoteness areas. Our findings highlights the importance of understanding differences in both culture and ease of access in relation to stimulant prescribing patterns for ADHD treatment.

Future research examining the cultural influences on ADHD treatment should include a qualitative approach to explore the parental country of birth differences in attitudes towards ADHD and its treatment, as well as financial and spatial barriers to access. It could also investigate if parental country of birth influences the stimulant medication use according to the gender of the child. Such research may shed light on whether over-prescribing or under-prescribing of stimulant medication is occurring within certain cultural groups and this may lead to possible avenues for alternative therapeutic approaches or improved accessibility to pharmacotherapy wherever this is warranted.

**Acknowledgements**

We thank Maternal and Child-Health Data Collection and the Data Linkage Branch of the WA Department of Health for providing the dataset for this investigation.

**References**

22. Moore S. Cultural perspectives on attention deficit hyperactivity disorder: A companion between culture and ADHD. Child Care Health Dev. 2010;36(3):333-44.
APPENDIX XII

Use of Prescription Stimulant for Attention Deficit Hyperactivity Disorder in Aboriginal Children and Adolescents: a Linked Data Cohort Study

Manonita Ghosh*, C. D'Arcy J. Holman and David B. Preen

Abstract

Background: Increasing recognition of Attention Deficit Hyperactivity Disorder (ADHD) among Aboriginal children, adolescents and young adults is a public health challenge. We investigated the pattern of prescription stimulants for ADHD among Aboriginal individuals in Western Australia (WA).

Methods: Using a whole-population-based linked data we followed a cohort of individuals born in WA from 1980–2005, and their parents were born in Australia, to identify stimulant prescription for ADHD derived from statutory WA stimulant prescription dispensing between 2003 and 2007. Parental link was ascertainment through WA Family Connections Genealogical Linkage System. Cox proportional hazards regression (HR) models were performed to determine the association between stimulant use and Aboriginal and non-Aboriginal status.

Results: Of the total cohort of 1,664,588, around 2% (n = 33,777) had prescription stimulants for ADHD. Individuals with both Aboriginal parents were two-thirds (HR 0.33, 95% CI 0.26–0.42), and with only Aboriginal mother were one-third (HR 0.69, 95% CI 0.53–0.90) less likely to have stimulants, compared to individuals with non-Aboriginal parents. HR in Aboriginal was 62% lower (HR 0.38, 95% CI 0.25–0.54) in metropolitan areas, and 72% lower (HR 0.28, 95% CI 0.20–0.38) in non-metropolitan areas, than non-Aboriginals. The risk for stimulant use was four times higher among Aboriginal boys than Aboriginal girls (HR 4.08, 95% CI 2.92–5.69).

Conclusion: Aboriginal cultural understanding of ADHD and attitude towards stimulant medication serve as a determinant of their access to health services. Any ADHD intervention and policy framework must take into account a holistic approach to Aboriginal culture, beliefs and individual experience to provide optimal care they need.

Background

Attention Deficit Hyperactivity Disorder (ADHD) has been defined as a common childhood-onset neurodevelopmental disorder characterized by severe inattention, impulsivity and hyperactivity which can be associated with significant educational and social impairment [1]. Psychostimulant medications such as methylphenidate and dexamphetamine are often recommended as a first-line modality for treating ADHD [2]. Despite extensive research into factors contributing to ADHD, the aetiology and pathogenesis of the condition are poorly understood. It may be influenced by a combination of genetic and environmental factors [3–5]. As is true with most mental and developmental disorders, there is not a definitive test for ADHD, because diagnosis and classification primarily rely on observed or self-reported behaviours. Moreover, the interpretations of the severity of these behaviours and whether they should be described as abnormal are subjective [6].

In Australia, there has been an increasing recognition of ADHD symptoms among Aboriginal children and adolescents than those in the non-Aboriginal population. Zubrick et al. [7] identified 15% Aboriginal children compared to 9.7% non-Aboriginals at the same age were...
at high risk of clinically significant hyperactivity. Yet, we do not have a clear understanding of the determinants that may account for this disparity. People with ADHD are over-represented in criminal justice system [8], and the rates of incarceration are reported high among Aboriginal young [9]. The prevalence of ADHD is higher among people living in low socioeconomic condition [10, 11]. It is well established that Aboriginal children are socially and economically disadvantaged with a lower life expectancy and less than equal opportunity. Whether the higher manifestation of ADHD symptoms in Aboriginal children and adolescents is a true prevalence of clinical ADHD, or their unique learning and behavioural patterns [12] that may erroneously lead to ADHD diagnosis poses a question.

There remains a dearth of research examining the degree to which ADHD behaviour is perceived as a problem and stimulant treatment is sought for ADHD in Aboriginal communities. Aboriginals place a holistic concept of mental illness including culture and spirituality, family and community kinships, historical, social and economic factors, fear, education and loss [13] which may construct a different attitude towards Western biomedical diagnostic labels and treatment for ADHD behaviour to that of mainstream Australians. This study reports the first whole-population-based Australian study of prescription stimulant pattern for ADHD among Aboriginals. In this paper the term “Aboriginal” encompasses both Aboriginal and Torres Strait Islanders as was approved as appropriate to use in scientific publications [14].

Methods

Study population

The study population comprised a retrospective cohort of all children, adolescents and young adults who were born in WA from 1980–2005, and their parents were born in Australia, and were stratified by their parents' Aboriginal and non-Aboriginal status. The cohort was then followed through to identify their first commencement of prescription stimulant for ADHD between 2003 and 2007. Records for stillbirths, parents born overseas, unknown/missing Aboriginal identity and death before 2003 were excluded, leaving 186,468 individuals for analysis. The selection criteria and process are shown in Fig. 1.

Data sources

Data were extracted from the WA Register of Birth, Death Registry, Midwives' Notification System (MNS) and Monitoring of Drugs of Dependence Systems through WA Data Linkage System which links databases using probabilistically matching techniques [15], and is known to achieve high level of linkage sensitivity (95–99 %) and specificity (98–99 %) [16]. The WA Family

![Diagram](image-url)
Connections Genealogical Database was linked to ascertain parent-child relationships [17].

Variables and measurements

The outcome measure was at least one record of prescription stimulant (methylphenidate and/or dextroamphetamine) dispensing for ADHD at any time during 2003–2007. Data was collected on a range of demographic factors including sex, Aboriginality, geographical remoteness, socioeconomic disadvantage and mother’s age. Parents’ Aboriginal status based on self-identification was derived from birth registry and MNS. The birth registry collects Aboriginal status of both parents, while the MNS collects information of the mothers only. Parents were recorded in birth registry as Aboriginal ‘Aboriginal/TSE, Torres Strait Islander’, ‘Yes Aboriginal’, ‘Not Aboriginal’, ‘Unknown’ and MNS data was coded as ‘Aboriginal/TSE, Caucasian’ and ‘other’. For this analysis all ‘Aboriginal’ and ‘Torres Strait Islander’ records were referral to as Aboriginals and ‘Caucasian’, ‘Not Aboriginal’ and ‘other’ records as non-Aboriginal. Aboriginal people are known to be under-identified or misidentified due to the fact that people may not be prepared to disclose their Aboriginal status depending on the situation [18]. Therefore, parents was considered Aboriginal if they had at least one record showing as an Aboriginal/Torres Strait Islander in either birth registry or MNS datasets. As such, a parent identified as Aboriginal in one dataset and non-Aboriginal in the other, was considered as Aboriginal to maximise reporting of Aboriginal people in this study [19].

Geographical remoteness was measured using the Accessibility/Remoteness Index of Australia (ARIA) [20] of the Australian Census, using whichever of the 1996, 2001 or 2006 indices were closest to the year of cohort entry. ARIA scores were grouped into three levels: metropolitan, rural and remote, with metropolitan used as the reference category indicating high accessibility according to residential postcode at the time of birth. Socioeconomic disadvantage was ascertained according to the Index of Relative Socio-Economic Disadvantage (IRSD), a summary measure of Socio-Economic Indexes for Areas (SEIFA) that focused on disadvantage in terms of accessibility to education, employment and income [21]. The IRSD scores were then grouped into quintiles ranging from most disadvantaged to least disadvantaged. Similar to ARIA, SEIFA score was derived from the national census years 1996, 2001, or 2006, using the index closest to the time of birth.

Statistical analysis

Descriptive statistics were calculated for all baseline demographic characteristics of the study sample, stratified by stimulant use group. The associations between stimulant use and potential predictors including gender, age, Aboriginality, geographical remoteness and socioeconomic disadvantage were investigated using univariate and multivariate Cox proportional hazards regression (HR) models with a follow-up time 31 of December 2007. Multiple linear regression models were also fitted to compare ages of individuals at initial stimulant use during 2003–2007. A two-sided p-value of <0.05 was considered statistically significant in all analyses. Missing values for each variable were entered as a separate exposure category in order to include all subjects in the analyses. Statistical analyses were performed with SPSS statistical software version 21.0.

Ethics approval

The study protocol adhered to guidelines for ethical conduct of Aboriginal health research, and was approved by the WA Aboriginal Health Ethics Committee (Ref No. 589), Human Research Ethics Committee of University of WA (Ref No. RA/4/1/2000), and Department of Health WA Human Research Ethics Committee (Ref No. 2009/21). As de-identified data was used in this study, individual consent was not required.

Results

Of the total cohort of 186,468 approximately 2% (n = 3677) of individuals had records of prescription stimulant for ADHD during the study period. Table 1 shows the socio-demographic profile of the stimulant and non-stimulant groups. The age at initial stimulant use ranged from 2–25 years with a mean age 8.7 years (SD 2.3). Individuals who had stimulant were mostly male (n = 2946, 80.1%), with non-Aboriginal parents (n = 3423, 95.1%), living in metropolitan areas (n = 2212, 62.3%), and least disadvantaged (n = 1299, 35.3%). Some 155 (19.5%) individuals had at least one Aboriginal parent, represented by only an Aboriginal father in 93 instances (2.5%), only an Aboriginal mother in 62 (1.7%) and by both parents being Aboriginal in 99 (2.7%).

Ethnic and demographic differences in stimulant use

Results of Cox regression analysis evaluating the associations between prescription stimulant use for ADHD and Aboriginality and other demographic characteristics are shown in Table 2. Both univariate and multivariate models showed that individuals with both Aboriginal parents were two-thirds less likely (adjusted HR 0.33, 95% CI 0.26–0.42, p < 0.001) and individuals with Aboriginal mothers only were one-third less likely (adjusted HR 0.69, 95% CI 0.53–0.93, p = 0.006) to use stimulants than individuals of non-Aboriginals parents. The risk for stimulant use in individuals of Aboriginal fathers was not significantly different from individuals of non-Aboriginal parents in either the crude or adjusted analysis. After adjusted, the association between risk for stimulant use and maternal age was marked. Individuals
Table 1 Baseline demographic characteristics of Aboriginal and non-Aboriginal children and adolescents born in WA between 1980–2002

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>No stimulant used (%)</th>
<th>Stimulant used for ADHD (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants</td>
<td>16224</td>
<td>3657</td>
</tr>
<tr>
<td>Parent/guardian</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aboriginal</td>
<td>1642/1642 (99.3)</td>
<td>24/32 (91.1)</td>
</tr>
<tr>
<td>Both parents</td>
<td>10724 (66.0)</td>
<td>99 (2.7)</td>
</tr>
<tr>
<td>Aboriginal</td>
<td>10724 (66.0)</td>
<td>99 (2.7)</td>
</tr>
<tr>
<td>Only father</td>
<td>992 (6.1)</td>
<td>93 (2.5)</td>
</tr>
<tr>
<td>Only mother</td>
<td>880 (5.4)</td>
<td>62 (1.7)</td>
</tr>
<tr>
<td>Only Aboriginal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother’s age at birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;20</td>
<td>1166 (6.9)</td>
<td>346 (6.4)</td>
</tr>
<tr>
<td>20–24</td>
<td>3300/130 (19.8)</td>
<td>950 (27.0)</td>
</tr>
<tr>
<td>25–29</td>
<td>407 (3.1)</td>
<td>116 (9.1)</td>
</tr>
<tr>
<td>30–34</td>
<td>5205 (25.6)</td>
<td>534 (22.7)</td>
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<td>35–39</td>
<td>18754 (10.3)</td>
<td>294 (9.1)</td>
</tr>
<tr>
<td>≥40</td>
<td>276 (1.5)</td>
<td>44 (1.2)</td>
</tr>
<tr>
<td>Unknown</td>
<td>244 (1.5)</td>
<td>6 (0.2)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9270 (56.7)</td>
<td>2946 (60.1)</td>
</tr>
<tr>
<td>Female</td>
<td>9003 (43.3)</td>
<td>2311 (39.9)</td>
</tr>
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<td>Unknown</td>
<td>2 (0.1)</td>
<td>0</td>
</tr>
<tr>
<td>Geographical remoteness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolis</td>
<td>10256/177 (67.8)</td>
<td>2212 (65.2)</td>
</tr>
<tr>
<td>Rural</td>
<td>40322 (22.1)</td>
<td>799 (21.7)</td>
</tr>
<tr>
<td>Remote</td>
<td>14160 (7.7)</td>
<td>171 (4.7)</td>
</tr>
<tr>
<td>Unknown</td>
<td>2272 (1.3)</td>
<td>45 (1.2)</td>
</tr>
<tr>
<td>Socioeconomic disadvantage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Least disadvantaged</td>
<td>78954 (42.8)</td>
<td>1299 (35.8)</td>
</tr>
<tr>
<td>Less disadvantaged</td>
<td>4061 (23.6)</td>
<td>845 (24.8)</td>
</tr>
<tr>
<td>Little disadvantaged</td>
<td>17057 (9.3)</td>
<td>395 (10.2)</td>
</tr>
<tr>
<td>More disadvantaged</td>
<td>8275 (4.7)</td>
<td>183 (5.0)</td>
</tr>
<tr>
<td>Most disadvantaged</td>
<td>15407 (8.7)</td>
<td>489 (13.3)</td>
</tr>
<tr>
<td>Unknown</td>
<td>2127 (1.2)</td>
<td>465 (12.7)</td>
</tr>
</tbody>
</table>

Comparison of stimulant use between non-Aboriginals and Aboriginals living in metropolitan and non-metropolitan areas:

In the adjusted model, individuals with both Aboriginal parents were 65 % less likely (HR 0.35, 95 % CI 0.25–0.49, \( p < 0.001 \)) in metropolitan, and 72 % less likely in rural and remote areas (HR 0.28, 95 % CI 0.20–0.38, \( p < 0.001 \)) to have stimulants than individuals with non-Aboriginal parents (Table 3). The HR was also lower in metropolitan, (HR 0.68, 95 % CI 0.68–0.95, \( p = 0.03 \)) and in non-metropolitan areas (HR 0.66, 95 % CI 0.64–1.20, \( p = 0.05 \)) for those who had only Aboriginal mothers. A 1.6 fold higher risk for stimulant use was seen in individuals of mother’s younger than 20 years old (HR 1.56 95 % CI 1.24–1.97, \( p < 0.001 \)) compared with mother age 25–29 years old. The higher risk for stimulant use among boys was observed in both metropolitan (HR 3.69, 95 % CI 3.31–4.19, \( p < 0.001 \)) and non-metropolitan areas (HR 4.29, 95 % CI 3.61–4.99, \( p < 0.001 \)). HR was elevated by two-fold in the most-disadvantaged group compared with their least-disadvantaged counterparts (metropolitan – HR 2.17, 95 % CI 1.89–2.49, \( p < 0.001 \), non-metropolitan– HR 1.80, 95 % CI 1.49–2.17, \( p < 0.001 \)).

Comparison of stimulant use within Aboriginal group:
The fitted univariate and multivariate models for stimulant use determinants in only those individuals who had any Aboriginal parents are shown in Table 4. Aboriginal boys were four times more likely to be prescribed than Aboriginal girls (HR 4.06, 95 % CI 2.92–5.69, \( p < 0.001 \)). Aboriginals living in remote areas were 62 % less likely (HR 0.38, 95 % CI 0.26–0.56, \( p < 0.001 \)) to have stimulants than their city counterparts. Mothers’ age and socioeconomic status were not significantly associated with stimulant use within this group. We also fitted a multiple linear regression model to examine the association between mean age at initial prescription and demographic and geographic variables, but no association was observed (results attached as Additional file 1).

Discussion:

Despite increasing recognition of ADHD among Aboriginal children [12, 22, 23], the risk of stimulant use for ADHD was markedly lower among individuals of Aboriginal parents than individuals of non-Aboriginal parents in our study. Parents are unlikely to pursue ADHD medication if they do not perceive ADHD as a clinical problem [24]. Aboriginal parents who allow children freedom to explore their environment without restrictions to make them physically and emotionally resilient [25], may perceive hyperactivity and impulsivity as normal child behaviour.
Table 2. Hazard ratios and 95% CI of prescription stimulant medication in Aboriginal and non-Aboriginal children and adolescents

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Univariate Analysis</th>
<th>Multivariate Analysis*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HR (95% CI)</td>
<td>P-Value</td>
</tr>
<tr>
<td>Parents' Aboriginal status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Aboriginal parents</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Both parents Aboriginal</td>
<td>0.45 (0.37-0.55)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Only father Aboriginal</td>
<td>1.13 (0.92-1.38)</td>
<td>0.26</td>
</tr>
<tr>
<td>Only mother Aboriginal</td>
<td>0.78 (0.61-1.01)</td>
<td>0.09</td>
</tr>
<tr>
<td>Mothers' age group in years at birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;20</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>20-24</td>
<td>1.44 (0.32-1.56)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>25-29</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>30-34</td>
<td>0.81 (0.75-0.90)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>35-39</td>
<td>0.84 (0.74-0.96)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>≥40</td>
<td>0.84 (0.62-1.13)</td>
<td>0.24</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Male</td>
<td>3.81 (3.3-4.35)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Geographical remoteness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Rural</td>
<td>0.95 (0.87-1.03)</td>
<td>0.18</td>
</tr>
<tr>
<td>Remote</td>
<td>0.88 (0.75-0.98)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Socioeconomic disadvantage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Least disadvantaged</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Less disadvantaged</td>
<td>1.21 (1.1-1.32)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Little disadvantaged</td>
<td>1.29 (1.25-1.56)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>More disadvantaged</td>
<td>1.31 (1.25-1.58)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Most disadvantaged</td>
<td>1.86 (1.70-2.08)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

*All parameters were included in the regression model so as to adjust each result for potential confounding by all other covariates.

Aboriginal children were subject to removal from their families historically through systematic policy of colonial intervention, and also to a lesser extent today through out-of-homecare programs [26, 27]. Parental separation and early attachment deprivation is a risk factor for ADHD in children [28]. Aboriginal parents may attribute hyperactivity and impulsivity to child-removal-associated trauma which has been rooted in the Aboriginal cultural memory [29]. This trauma has been advanced as a reason why treatment may appear to the Aboriginal parents as a repetition of the colonial practices [30], jeopardising abilities to fulfill their roles in family and community [31].

Stimulant use was notably lower in individuals of Aboriginal mothers than fathers, possibly due to the fact that Aboriginal women traditionally play a central role in family and community, and are solely responsible for caretaking and early child socialization [32, 33]. Conversely, another study reported fathers more than mothers were associated with lower stimulant use in non-Anglophone Australian communities [34]. The authors argued that fathers who were less likely to perceive ADHD as a problem than mothers were the decision-maker about child health in non-English speaking communities.

We found lower risk of stimulant use among Aboriginals in non-metropolitan than in metropolitan areas likely due to geographical disparities in healthcare service access with shortages of health-related infrastructure in rural areas in Australia [35]. Positive impact of community support and sense of belonging on protecting Aboriginal people against mental illness in both metropolitan and remote Aboriginal communities in Australia are documented [36, 37]. Yet, it is difficult to measure if the influence of the community support on mental health is greater in rural than metropolitan communities. In Canada, Currie et al. [38] reported that while Aboriginal enucleation was protective against substance use and strengthened psychological wellbeing, mainstream acculturation weakens the influence of cultural ties and was a risk factor for substance abuse in urban Aboriginal adults. As Aboriginal people continue to urbanize in Australia [39], they may adopt beliefs and attitudes to ADHD medication of the mainstream urban society leading to the discrepancy in stimulant use between metropolitan and remote Aboriginal communities here.

We made a number of other salient observations in this study. The first confirmed the well-known gender variation in stimulant use. Both Aboriginal and non-Aboriginal boys had elevated risk of stimulant use...
Table 3  Comparison of stimulant medication in Aboriginal and non-Aboriginal children by metropolitan and non-metropolitan areas

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Multivariate Analysis</th>
<th>Multivariate Analysis*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Metro (HR 95% CI) P Value</td>
<td>Non-Metro (HR 95% CI) P Value</td>
</tr>
<tr>
<td>Parents Aboriginal status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Aboriginal parents</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Both parents Aboriginal</td>
<td>0.33 (0.26-0.41) &lt;0.001</td>
<td>0.29 (0.20-0.39) &lt;0.001</td>
</tr>
<tr>
<td>Only father Aboriginal</td>
<td>0.96 (0.73-1.26) 0.75</td>
<td>0.89 (0.55-1.42) 0.65</td>
</tr>
<tr>
<td>Only mother Aboriginal</td>
<td>0.69 (0.40-1.11) 0.20</td>
<td>0.66 (0.44-1.00) 0.051</td>
</tr>
<tr>
<td>Mothers' age group in years at birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;20</td>
<td>1.19 (1.01-1.41) 0.020</td>
<td>1.32 (1.02-1.70) 0.031</td>
</tr>
<tr>
<td>20-24</td>
<td>1.48 (1.33-1.66) &lt;0.001</td>
<td>1.60 (1.36-1.88) &lt;0.001</td>
</tr>
<tr>
<td>25-29</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>30-34</td>
<td>0.89 (0.77-1.02) 0.04</td>
<td>0.85 (0.71-1.01) 0.07</td>
</tr>
<tr>
<td>35-39</td>
<td>0.89 (0.73-1.04) 0.07</td>
<td>1.06 (0.92-1.23) 0.67</td>
</tr>
<tr>
<td>≥40</td>
<td>0.78 (0.53-1.16) 0.22</td>
<td>1.00 (0.55-1.83) 0.99</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
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<tr>
<td>Female</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Male</td>
<td>3.69 (1.33-10.00) &lt;0.001</td>
<td>4.24 (1.61-10.98) &lt;0.001</td>
</tr>
<tr>
<td>Socioeconomic disadvantage</td>
<td></td>
<td></td>
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<tr>
<td>Least disadvantaged</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Less disadvantaged</td>
<td>1.10 (0.87-1.38) 0.60</td>
<td>1.15 (0.96-1.36) 0.13</td>
</tr>
<tr>
<td>Little disadvantaged</td>
<td>1.33 (1.16-1.53) &lt;0.001</td>
<td>1.38 (1.04-1.84) 0.02</td>
</tr>
<tr>
<td>More disadvantaged</td>
<td>1.40 (1.16-1.69) &lt;0.001</td>
<td>1.73 (1.45-2.10) 0.03</td>
</tr>
<tr>
<td>Most disadvantaged</td>
<td>2.17 (1.89-2.48) &lt;0.001</td>
<td>1.60 (1.49-1.70) &lt;0.001</td>
</tr>
</tbody>
</table>

*All parameters were included in the regression model so as to adjust each result for potential confounding by all other covariates.

Table 4  Hazard ratios and 95% CI of prescription stimulant medication in Aboriginal children and adolescents

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Univariate Analysis</th>
<th>Multivariate Analysis*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HR (95% CI) P Value</td>
<td>HR (95% CI) P Value</td>
</tr>
<tr>
<td>Mothers' age group in years at birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;20</td>
<td>0.70 (0.47-1.04) 0.28</td>
<td>0.69 (0.45-1.11) 0.10</td>
</tr>
<tr>
<td>20-24</td>
<td>1.10 (0.80-1.50) 0.55</td>
<td>1.20 (0.85-1.69) 0.29</td>
</tr>
<tr>
<td>25-29</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>30-34</td>
<td>1.06 (0.72-1.57) 0.78</td>
<td>1.33 (0.86-2.03) 0.22</td>
</tr>
<tr>
<td>35-39</td>
<td>0.98 (0.54-1.77) 0.39</td>
<td>1.20 (0.68-2.14) 0.48</td>
</tr>
<tr>
<td>≥40</td>
<td>0.49 (0.26-0.93) 0.44</td>
<td>0.40 (0.21-0.82) 0.01</td>
</tr>
<tr>
<td>Sex</td>
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<tr>
<td>Female</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Male</td>
<td>4.5 (2.17-9.32) &lt;0.001</td>
<td>4.00 (2.39-6.59) &lt;0.001</td>
</tr>
<tr>
<td>Geographical remoteness</td>
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<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Rural</td>
<td>0.89 (0.61-1.31) 0.23</td>
<td>0.88 (0.60-1.22) 0.20</td>
</tr>
<tr>
<td>Remote</td>
<td>0.49 (0.27-0.86) 0.03</td>
<td>0.38 (0.22-0.66) 0.001</td>
</tr>
<tr>
<td>Socioeconomic disadvantage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Least disadvantaged</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Less disadvantaged</td>
<td>1.05 (0.68-1.63) 0.82</td>
<td>1.10 (0.74-1.63) 0.63</td>
</tr>
<tr>
<td>Little disadvantaged</td>
<td>1.29 (0.76-2.19) 0.03</td>
<td>1.20 (0.74-2.03) 0.29</td>
</tr>
<tr>
<td>More disadvantaged</td>
<td>1.03 (0.65-1.60) 0.71</td>
<td>1.20 (0.74-2.03) 0.39</td>
</tr>
<tr>
<td>Most disadvantaged</td>
<td>1.14 (0.76-1.72) 0.51</td>
<td>1.40 (0.92-2.12) 0.12</td>
</tr>
</tbody>
</table>

*All parameters were included in the regression model so as to adjust each result for potential confounding by all other covariates.
possibly due to the fact that boys commonly manifest hyperactivity and impulsivity [40] which may closely coincide with previous and gender stereotypes influencing referral [41] and diagnosis [42]. Secondly, the association between young maternal age and increased stimulant use risk was well established [43–45]. A high level of maternal depression, smoking and substance use during pregnancy has been reported as risk factors for ADHD in children [44, 45]. This association was not marked in Aboriginal groups here, and may need further research. Thirdly, associations between socioeconomic hardship and increased stimulant use was in line with previous Australian studies [34, 40]. While a high prevalence of ADHD in marginalized children is well established [10, 46], a large proportion of Australian children living in poverty were reported as being treated without meeting the ADHD diagnosis criteria [47, 48]. Hence, disadvantaged children who are more likely to be diagnosed with ADHD represent an important public health issue. Yet our findings of no association between disadvantage and stimulant use within Aboriginal groups is novel, however different interpretations exist and further investigation is warranted. One possibility is that within the Aboriginal population, social disadvantage correlates with ADHD symptoms and with a tendency not to receive treatment. Community support and cultural bond which have been shown to buffer mental and behavioral problems for marginalized people [49] could be another explanation.

Some limitations need to be considered when interpreting our results. The datasets did not permit identification of individuals diagnosed with ADHD but not prescribed stimulants. It would have been useful to examine differences between diagnosis rates and stimulant treatment among Aboriginal children to investigate the likelihood of stimulant over- or under-prescribing. In order to correctly identify Aboriginal people we triangulated information from two data sources; yet, it is still possible that Aboriginality is under-reported or mis-reported. It is also possible that our results were affected by unmeasured and, as yet, unidentified confounders.

Conclusion

Lower stimulant use for ADHD in children and adolescents of Aboriginal parents in our study suggests either Aboriginal parent perceive ADHD symptoms as normal child behaviors; have a negative attitude towards medication; or cultural competency provides a coping mechanism to make the ADHD symptoms functional. Alternatively, Aboriginal children who would stand to benefit from ADHD medication may face barriers to access. Aboriginal children should be protected from misdiagnosis and over-diagnosis; however, great care should be taken to ensure full access to appropriate services when required. A better understanding of Aboriginal perceptions of ADHD and stimulant treatment is crucial to identify vulnerabilities and develop targeted interventions and policy that account for social factors and align with Aboriginal culture to provide optimal care. We suggest two avenues for future research examining ADHD prevalence in Aboriginal children with narrowing of focus: first, for the rate of ADHD diagnosis and stimulant treatment to be investigated; and second, qualitative research to explore Aboriginal perception towards ADHD and stimulant treatment.

Additional file

Additional file 1: Mean age in years at initial prescription in those receiving a stimulant medication for ADHD according to cultural and demographic factors. (DOCX 18 kb)

Abbreviations

ADHD: Attention-Deficit Hyperactivity Disorder, AIHW: Australian Institute of Health and Welfare, BHC: Bureau of Internal Revenue, NSSE: Socio-Economic Indexes for Areas, WA: Western Australia.

Competing interests

NS and COH participated in the conception, study design and formulation of data analysis plan. NS carried out the data analysis, and prepared the manuscript. COH reviewed the manuscript and contributed to the discussion. DJP critically revised the manuscript for important intellectual content and advised on the method. All authors read and approved the final manuscript.

Acknowledgements

We are thankful to the Data Linkage Unit, WA Department of Health for extracting, linking and providing access to the datasets. We also thank the custodians of the pharmaceutical, genealogical and child-related data collection at the WA Department of Health, WA Registry of Births and Deaths for the provision of service data for this investigation.

Received: 25 July 2015 Accepted: 18 November 2015
Published online: 09 December 2015

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“It has to be fixed”: a qualitative inquiry into perceived ADHD behaviour among affected individuals and parents in Western Australia

Manonita Ghosh1*, Colleen Fisher2, David B. Preen1 and C. D’Arcy J. Hoffman1

Abstract

Background: The use of stimulant medication for Attention Deficit Hyperactivity Disorder (ADHD) to improve classroom behaviour and sustained concentration is well known. Achieving a better academic grade has been reported as the prime motivation for stimulant use and is an increasingly discussed topic. The proliferation of stimulant use for ADHD has been a cause for public, medical and policy concern in Australia. This paper explores individuals’ perceptions of ADHD, the meaning that the diagnosis carries for them and their attitudes to stimulant medication treatment.

Methods: This qualitative study was undertaken by a social constructivist approach and involved semi-structured interviews with eight participants. The participants were parents of children with ADHD or were adults who themselves had been diagnosed with ADHD. Interviews were audio-taped, transcribed verbatim and thematically analysed.

Results: There were three interrelated yet contradictory overarching themes: (1) An impairment to achieving success, which can be a double-edged sword, but has to be fixed; (2) Diagnosis as a relief that alleviates fault and acknowledges familial inheritance; (3) Responsibility to be normal and to fit in with societal expectations. Collectively, these perceptions and meanings were powerful drivers of stimulant use.

Conclusions: Paying attention to perceptions of ADHD and reasons for seeking or not seeking stimulant treatment is important when planning appropriate interventions for this condition.

Keywords: ADHD, Stimulant medication, Qualitative study, Social constructivism, Thematic analysis

Background

Attention Deficit Hyperactivity Disorder (ADHD) is defined as a chronic neuro-developmental disorder characterised by the core symptoms of hyperactivity, impulsivity and inattention [1]. It affects more than 7% of children [2] with a higher prevalence among boys [3]. There has, however, been considerable argument surrounding the aetiology of ADHD, questioning whether it is a neuro-genetic condition or a socially constructed illness [4]. The debate is fuelled in part by the general if not ambiguous nature of ADHD symptoms defined in the DSM-V [1]. Some argue that children often display behavioural characteristics that include features analogous to the symptoms of ADHD, such as hyperactivity and inattentiveness [5]. Additionally, the treatment of ADHD with psychostimulant medication has been controversial and the focus of much debate in developed countries including Australia, due to the subjectivity of the diagnosis as well as the ethics of treating children long-term with substances that have the potential for abuse [6, 7]. Much attention has also been paid to the short and long-term effects of stimulant use including the risk of cardiovascular complications [8].

Prescriptions for stimulant medication have risen sharply in Western countries over the last decade [9–11]. In Australia, the rate of stimulant treatment rose 72% between 2000 and 2011 [12], representing an average...
annual growth of 4.7% and exceeding estimated growth rates in the US by 1–2% [13]. The persistent rise reflects widening diagnostic criteria [14], an increase in studies purporting benefits from early recognition of ADHD and the efficacy of stimulant medications [15], effective marketing by pharmaceutical companies and a greater acceptance of stimulant treatment among health professionals [16]. This proliferation of stimulant treatment has been cause for public concern that too many children are diagnosed with ADHD and treated with stimulant medications when they do not actually have a disorder [17]. The stimulant medications that are recommended by American Academy of Paediatrics [18] may lessen the severity of ADHD symptoms, increase attention and concentration, and improve classroom behaviour [19]. However, it has been noted that short-term stimulant treatment showing improvement in childhood does not necessarily have lasting effects into the adolescent years [20]. Further, the medications do not promote learning or improve cognitive ability [21]. Nevertheless, it has been reported that they are used for the purpose of neurocognitive enhancement [6]. Parents are more likely to adhere to stimulant treatment if their child has a cognitive impairment [22]. Achieving better academic grades and enhancing cognitive performance is reported to have been the prime motivation for stimulant use among asymptomatic students who signed the features of ADHD in order to obtain prescriptions [23].

In light of polarised debate, yet increasing use of stimulant treatment, individuals’ perceptions and experiences related to their child’s or their own diagnosis and treatment are important, but have largely been ignored. Taylor et al. [24] suggested that parents’ decisions to administer psychostimulant treatment are based on their own blend of personal experience, observations of societal norms and media reports. Understanding individuals’ perceptions of and attitudes towards stimulant treatment is important for appropriate intervention and proper management. Understanding which members of the community are more willing to accept stimulant treatment and the factors that make stimulant use more acceptable would be helpful to avoid over-diagnosis and overtreatment.

This study used a qualitative approach to understand how parents of children diagnosed with ADHD, as well as adults diagnosed with ADHD perceived ADHD behaviour and stimulant treatment. The objectives of this study were to explore individuals’ perceptions of ADHD behaviour, the meaning that the diagnosis carries for them, and their attitudes to stimulant treatment derived from their everyday experiences.

Methods
The qualitative approach used for this research was underpinned by a social constructivist philosophical stance, which emphasized the way individuals seek to understand their world and construct their own particular meanings that correspond to their experiences [25]. It assumes that knowledge and truths are created by the individual’s everyday interactions [26]. Constructivism therefore assisted in the understanding of how the participants in this study perceived ADHD behaviour and stimulant treatment.

Sample
Participants were recruited through volunteer sampling. An information sheet was distributed to primary schools, Department of Health Western Australia (WA) facilities, and the Learning and Attentional Disorder Society Support Groups in WA. A snowball technique in which participants were contacted via networks was also employed [27]. Participants were selected based on the following criteria [28]: those who themselves were diagnosed or had dependent children diagnosed with ADHD; aged over 18 years; and were able to converse fluently in English. We received expressions of interest to participate in this study from ten people with similar ethnic and socioeconomic backgrounds. Data saturation was reached after collecting information from eight participants as no further new themes emerged from the analysis [29]. The participants were aged 30–60 years, seven of whom were female and all were English speaking and resided in the Perth metropolitan area (see Table 1). The sample comprised six parents of children with ADHD (aged 3–23 years), one grandmother of an ADHD child aged 17 years and one childless adult diagnosed with ADHD and depression. Four parents had more than one child diagnosed with ADHD. Three parents were also diagnosed with ADHD at ages 40–45 years and another two were diagnosed with depression. All participants described their race as Caucasian with five born in Australia and three born in the US, UK and South Africa respectively. Of those born overseas, two had been living in Australia for 22–26 years and the third immigrated 15 years prior to starting a family. They all had university degrees, five were professionals, two were stay-at-home parents and one was a student.

Data collection procedure
In order to understand the individuals’ perceptions towards ADHD behaviour, after obtaining signed consent to participate, semi-structured face-to-face in-depth interviews were conducted to capture participant beliefs and thoughts in their own words [30]. Seven key questions guided the interview sessions were (See Additional file 1 for demographic and interview questions):

1. How was the decision made to seek for professional help?
2. How did you feel being/your child being diagnosed with ADHD?
Table 1 Demographic characteristics of the study participants

<table>
<thead>
<tr>
<th>Sex</th>
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<table>
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<table>
<thead>
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<table>
<thead>
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</tr>
<tr>
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</tr>
<tr>
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<table>
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<tr>
<td>Graduate</td>
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</tr>
<tr>
<td>Post graduate</td>
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<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Depression</td>
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</tr>
<tr>
<td>Had children with ADHD</td>
<td>3</td>
</tr>
<tr>
<td>One child</td>
<td>4</td>
</tr>
<tr>
<td>More than one child</td>
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<tr>
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<table>
<thead>
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<tr>
<td>Father</td>
<td>1</td>
</tr>
<tr>
<td>Grandmother</td>
<td>1</td>
</tr>
<tr>
<td>Adult with no children</td>
<td>1</td>
</tr>
</tbody>
</table>

3. Who do you think is responsible for this condition (ADHD)? Why
4. How was the decision made to administer medication?
5. How do you feel about administering medication for ADHD?
6. How was your/child’s behaviour and your decision to administer medication received by your family and friends?
7. How did their response make you feel? How did you want them to make you feel?

The semi-structured interview kept the discussion on track within the available time restraints. Each interview lasted approximately one hour. This was long enough to encourage participants to talk freely, but not too long to tire them. To keep all interviews consistently focused

yet uninhibited, each participant was asked the same questions, but with a change in the order of questions as appropriate to maintain the flow of the interview. Additional open ended questions were used as prompts, depending on the nature of the discussion. With each participant’s permission all interviews were audio-recorded. The interviews took place at participants’ homes or at other alternative participant-nominated locations to allow them to retain some control over the interview situation and to render the interview session non-threatening, comfortable and convenient for them [31].

Data analysis
Thematic analysis of participants’ transcribed interviews was conducted. Thematic analysis is a qualitative "method for identifying, analysing and reporting patterns (themes) within data” [32] (P. 79). Thematic analysis is appropriate for exploring and understanding individuals’ experiences, which are often multi-dimensional and multi-layered, whilst elucidating various aspects of the research topic. Braun and Clarke [32] have defined six phases of conducting thematic analysis: familiarising with the data; generating initial codes; searching for themes; reviewing themes; defining and naming the themes; and report producing. Audio recordings of all interviews were transcribed verbatim and the transcriptions were carefully read several times to become familiar with the data to obtain a holistic appreciation of participants’ experiences. Salient words, phrases and sentences used by the participants were highlighted in this phase. Participants’ statements or moments of experience were then initially coded so as to capture their ideas. Next codes were collated into potential overarching themes and sub-themes. In the fourth phase, all overarching themes and sub-themes were then re-checked against the coded data extracts, as well as the entire original transcriptions and refined to ensure an authentic reflection of the participants’ experiences. This phase necessitated a more focused analytical ordering of themes and subthemes. The next phase involved generating definitions and names for each theme to tell the overall story. The final phase of the data analysis consisted of selection of vivid and compelling extract examples, relating the analysis back to the research question and literature. The first author carried out the data collection and data analysis and other co-authors contributed to study design, formulation of data analysis plan and interpretation of findings.

Rigour
An in-depth face-to-face interview method was used to explore individuals’ perceptions and beliefs towards ADHD and stimulant medication use in their own words.
Therefore, the research method was anchored in the constructivist tradition to construct knowledge, meaning and understanding through human interactions, and so the trustworthiness was ensured in the course of conducting this study [33]. Rigour was also enhanced through familiarity with and continual immersion in the data at every step before and during analysis [32]. The validity of individual overarching themes and sub-themes in relation to the data set was ensured through continual revision and checking of coded data extracts and transcriptions, individually and collectively, to reflect accurately the meanings evident in the data as a whole [32]. Producing the research findings to tell the complex story of the participants’ perceptions and experiences was another way to ensure the validity of the analysis [32].

Ethics approval
The study adhered to ethical principles according to the National Health and Medical Research Council guidelines for conducting human research [34]. Ethical clearance was obtained from The University of Western Australia Human Research Ethics Committee (RA/6/1/2000). As part of this approval, each participant received a written participant information sheet, advising that participation was voluntary and assuring the person that they could decline to answer any question that they felt uncomfortable with and that they were at liberty to withdraw at any time without consequence. The anonymity of the participants was protected by using pseudonyms.

Results
The analysis of the interviews revealed three overarching themes with two sub-themes for each. In sharing their experiences, participants touched on many common themes, yet sometimes these were in indirect contradiction to one another, demonstrating the complexity of the topic. Collectively, the interrelated yet contradictory perceptions and meanings were powerful drivers of stimulant use and are illustrated in Fig. 1.

An impairment to achieving success
It’s a double-edged sword
In discussing their experiences the participants expressed their negative and positive views towards ADHD. Parents reflecting on their experiences of their children suggested that children with ADHD were ‘difficult to manage’, ‘challenging’, ‘exhausting’, ‘not normal’ and had something ‘wrong’ in them. The parents stated that ADHD had a profound impact on their children’s learning at school and noticed ‘lack of concentration’, ‘struggling with school work’, ‘not achieving at school’ and ‘not being interested’. Some noticed an emotional roller-coaster in their children and one felt that her son was suicidal.

I didn’t realise that the emotional problem that [my son] was experiencing was direct result of ADHD. I know he was hyperactive, but I didn’t know the emotional difficulties he had. I didn’t understand the impact of ADHD he had. I just saw the hyperactivity thing...struggling at school...but by the time he was 15, things were coming apart and really I did worry that he would suicide. (Jo)

As adults, participants described similar experiences including ‘lack of concentration’, ‘unable to remain seated’, difficulties in ‘waking up in the morning’, ‘organising tasks’ and ‘working with co-workers’.

Despite the difficulties they experienced, as parents, the participants often added positive attributes of their child’s ADHD for higher physical energy levels and cognitive abilities. Some believed that people with ADHD could be highly intelligent, and articulated that ADHD symptoms could be seen among famous people like ‘Aristotle’ and ‘Einstein’ throughout history. Annette had two of her children diagnosed with ADHD, and she thought:

First it was a curse, it was so hard to control; it pulls them so difficult, they turn of their different feelings [sic]; But other side some of the things they do are amazing. It is like a gift, having extra special power, but whether you can control them?

Jo perceived a positive side of ADHD along with its negative connotation. She found her ADHD child was fun:

He was intellectually challenging and fun to rear...interesting...creative so far out of the box...you have to have eyes in the back of your head...never a dull
moment... exhausting and emotionally scarring but incredibly interesting... intellectual stimulus... you can put it ... that way.

Jo was also diagnosed with ADHD and taking medications. She compared her life to her friends' lives, and described:

They [her friends' lives] are organized and dull — my one is chaotic and fun. We see more funny connection than other people see — more interesting... one of my friends said I was lot more fun before [treated].

She then added when she was asked about her perception towards ADHD:

I think about this a lot and I'm not sure. We read a lot about those outstanding individuals for whom ADHD has been a blessing that they have made great discoveries and they are enormously successful.... There was a belief that human cloning would not succeed without ADHD people in the society ... [but] the flip side of me says, the success stories that ... you do not hear about people who had their life in hell because of the emotional difficulties that ADHD creates. My son and I talked about this a lot. We both agreed [that]... the technical as we call the life we live is not worth, we prefer the black & white that everybody lives. So... it's a double edged sword....

It has to be fixed

Predominantly, however, ADHD was viewed as a 'problem' and a 'disability' that needs to be cured. Participants frequently mentioned the impact of ADHD behaviour: on their child's inability to 'achieve' at school and 'function properly' in society. They believed academic achievement is the key to success in life, and everybody should strive for success. Participants perceived ADHD as an 'impairment' to achieving 'success'. As Susan stated:

We need to fix the problem. If he is not achieving at school what he is supposed to achieve and there is a problem, then do whatever it needs to be done to fix it....

Kate's perspective was similar:

We think ADHD is impairment to success. We think success is everything. You got to be successful in life, academically and financially successful. You need to achieve regular goals, family, kids. So, this is impairment, something to be cured... it has to be fixed.

Diagnosis as a relief

It's not my fault

'Diagnosis as a relief' was the vernacular that all participants expressed knowing that the condition was a 'neurobiological disorder' caused by 'missing chemicals in the brain' and so was not their fault. The diagnosis relieved them from anxiety and stress, and provided reassurance that they or their children were not 'bad' or 'naughty', 'lazy' or 'stupid'. The relief was also closely linked with the sense that there is help available, as Cheryl expressed:

I was pleased to find out that there was something we could do because my son was really struggling. So it was very good for us to find out what the cause was of his problem... a big relief because he was clearly intelligent but he was clearly struggling.

Linda described her feelings after she was diagnosed with ADHD:

I actually felt relief. I was relieved because I realized that I was neither mad nor bad. There was certainly evidence that made other people to feel that I was bad... sometimes I thought am I crazy? People said I am rude, I am this and that. I am mad... but I thought I had a good heart... I am concerned about people's wellbeing and I wanted to help...now I know why.

The diagnosis served parents as a means of validating their parenting skills. They felt relief from a burden of guilt about being bad parents who could not discipline their children. As he felt:

... relaxed, thankful, happy, probably validated. Along the way we tried couple of others because he [son] had learning difficulties despite his intellect, we had him tested various other types of psychologically tested. They said he had learning difficulties associated with eye sight tracking which is very common with ADHD ... but he had two other diagnoses that both said that I was an over protective mother that caused those lesions... so I was causing his problem. They said I was the problem, not him... it was all my fault and he had nothing wrong with it. So when he was diagnosed very comprehensively to fulfill more than minimum criteria [for ADHD], or maximum whatever you could have, it was a validation for him and for me. For him it was giving a name and understanding of why he was different.

All participants had a biomedical understanding of ADHD and recognized it as a medical condition, but did not perceive this condition as a mental illness. As Fiona (grandmother) described her grandson's ADHD:
He is missing a chemical that doesn’t allow his brain to do what he needs to do. His brain is seeking stimulation or lacking the ability... it’s not an illness, but it’s a disability, because his body can’t do certain things.

Kate acknowledged that according to diagnostic criteria – the Diagnostic and Statistical Manual of Mental Disorder [1], ADHD is a mental illness, but she was reluctant to believe that her son had a mental illness:

"Well, ADHD is a mental health issue in the DSM 4 and 5. According to that, he has it, but I don’t think about it to be honest... I don’t see him mentally... but if not treated it can be a mental health issue... so we accommodate for his [ADHD], so he won’t have any serious mental health problems."

While the participants were reluctant to accept ADHD as a mental illness, they accepted this condition as a disability. It appeared that the disability status of ADHD might serve as a purpose for two of the parents. Annette, who had two of her children diagnosed with ADHD, found that school staff were supportive and they understood ADHD as a disability, and accommodated her children’s needs with special care as necessary. She, however, became "frustrated" with the social security personnel who did not think of ADHD as a disability and did not think Annette should be eligible for a caregiver allowance for children with disabilities. However, Linda did not perceive ADHD as a mental health problem, but believed it as a disability, was able to secure her disability pension for ADHD.

It runs in the family

The relief was closely tied with perceiving ADHD as a genetic condition and realising that it ran in other family members. The participants mentioned that after one child was diagnosed, they started noticing similar symptoms in their other children and in other family members. Three of the participants were diagnosed after their children were diagnosed. Patrick was one of them:

"My two older boys were diagnosed first, and listening to the paediatricians I realised that me and my wife had the same symptoms... so it came through our lines, therefore it was genetic and heritage ran from us... so we were treated.

Annette defended herself saying that she tried her best to be a ‘good mother’ during her pregnancy and afterwards doing ‘everything right’ and confirmed that ADHD was not her fault but a genetic disorder.

When I was pregnant, I did nothing wrong – no drinking, no drug, no bed food. I did everything by the book. I pumped myself from everything to be the best mother... since they were little I gave them boundaries, they were not allowed to have soft drinks, sugar... so, that was not the case... if ADHD was from the family... it’s genetic, it’s through the generation... through the father... while doing this [treatment for the first child] we sort of knew my husband had had it for a very long time. So we got him diagnosed... it’s hereditary... since my husband was diagnosed, my father-in-law with full of ADHD... in his 60s... said to me “I know I’ve got it.”

Responsibility
To be normal

Responsibility focused on parents’ abilities to solve the problem their child was experiencing at school and how stimulant medications helped the parents to fulfill their responsibilities. When describing the effect of medication, the parents and grandmother in the study placed emphasis on their child’s academic outcomes. The medication helped their child to "slow down" and to engage ‘straight away’, which helped the child to ‘focus’, concentrate better and 'stay on task' at school. The parents frequently mentioned that their child achieved higher grades after taking medications. These parents said that the school teachers were also happy with the change in their child’s behaviour. For two parents, medications were believed to improve the ‘quality of life’ of the child.

A few participants reported unpleasant effects of the stimulants, such as ‘mood swing, weight loss’, ‘decreased appetite’, ‘heart going faster’ and ‘trouble with sleeping’. They mentioned that their child was prescribed ‘Catapres’, which was usually prescribed for high blood pressure, to reduce the side effect of the ADHD stimulants. All parents acknowledged stimulants as the most ‘evidence based’ effective treatment. Four recognised the stimulant as an ‘important part’ of the ADHD treatment strategy, but as only ‘a part’, and said that their child also required psychotherapy, counselling, learning and behavioural management.

All parents reported in initial hesitation about using stimulant treatment, and expressed concern that the medication was ‘not good for health’. The grandmother mentioned that her initial resistance to medication was due to ongoing debate in the public sphere about over-diagnosis of and over-medication for ADHD. Two parents exhausted alternative therapies before they agreed to stimulant medication. As Cheryl noted:

...it’s not the decision that parents make easily. Any long term medication that you put your child on – this is something you have to think about long and hard.
You have to decide that your child is diagnosed with something you have to be satisfied with ... worry and throw in ... We tried occupational therapy ... all sorts of things and wasted lots of money ... but when it was clear that none of these were happening — it was already two years. Actually it was my biggest regret that I didn't try with the medication at the beginning. He would have learnt a lot more at school in those two years.

Parents felt it was their responsibility to boost their child's self-esteem' to make them feel 'normal', so that they could 'fit in' society. Annette felt strange with the idea of giving medication to manage behaviour initially; however, she convinced herself, thinking that giving stimulants to her children for ADHD was similar to taking blood pressure medication for herself. As such, she realised that she must not feel guilty about giving the ADHD medication, because it was her responsibility as a 'good mother' to help her children to improve their self-esteem and to allow them to fit into the community. As she articulated:

I felt strange ... but now it is a normal way of life and I don't have a problem with it. So I don't feel guilty about giving [medication] to them [the children]. As a parent, it is my responsibility to give them ... it is no different to my blood pressure tablet. I have to take blood pressure tablet or I would feel ill ... So, it's [medication] a tool for them to cope. To me, it's a tool to not feel inadequate, not feel different. I don't want them to be in trouble. I don't want them to feel that there was something wrong with them ... it's about self-esteem, confidence ... about fitting in ... learning, adaptation ... So they have their routine, and they have to take the medication every day to be normal.

In many instances within the interviews the participants defended others' perceptions of their ADHD behaviour or that of their children. They tried to move beyond what other people perceived about themselves and also any feeling of guilt that troubled them about giving medication to their child. They appeared to be justifying their decision to adhering medication treatment. They advocated for ADHD as a disability and the use of medication as an acceptable treatment choice. They believed that by educating others they would normalise ADHD, destigmatise stimulant treatment, and improve the outcomes of their and their child's ADHD. Through this role, they constructed themselves and their child as normal. Patrick and Cheryl took on the position of educators for managing ADHD and stimulant treatment. Annette raised money for an ADHD charity. She and her husband, who was also diagnosed with ADHD, "proudly wore t-shirts saying it was superme ADH mosaic me with superpower! I've forgotten my needs today so that [their] kids have a role model". Annette also worked hard to educate other parents and children about ADHD so that other children would find her children 'normal' and 'average'. As she described:

So, I try to make it open as much as possible. I brought the book, and the teachers read with other kids that [her son's name] has a brain, and he can't concentrate. So the whole class would know — that's how the teacher is educating the children. There is nothing wrong with [her son's name], he has taken medication to calm down. So if the parents think that way, it should come from the children that [her son's name] is not naughty, not a bad kid and he does not have any problem. I used to bring all books and DVD of ADHD and gave it to teachers to guide it to other parents, because I wanted to have others to be educated.

To fit in

Susan also expressed her concern about giving medication to her child, but she justified her decision by saying that as a 'responsible mum' it was her duty to make her son fit into school and, therefore, she needed to continue with the medication. To minimise the harm of the medication and to allow her son to 'learn to be himself', she gave him a break from medication on school holidays.

I feel I am doing the right thing, but I wish I didn't have to ... I don't like it [giving the medication], but I have to do it for his education. It's a drug and it is not good for your body ... so on school holidays I don't give it to him, he doesn't need it for any reason, because he is what he is. So he can learn to be himself without the pill ... but he has to go to school and do what he is told to do and to fit in. If he was diabetic, he had to have the medication. So I feel to be a responsible mum, he has to have it. I can't change the way he wants to be ... that's not responsible parenting ... that's wrong ... giving him wrong expectations — so he has to take the pills ... responsibility is you have to do what you have to do. If he is happy with his life later on not to take it that would be his adult decision, [but] I will guide him until then.

Susan, however, did not get her older son, who she thought also had ADHD, diagnosed and treated, because his condition was not affecting his education. She thought because he was 'getting away with his school work' she did not need to 'medicate' him. Through
comparing ADHD medication to that taken for chronic diseases, such as diabetes or blood pressure, the parents emphasised the medication’s role in their child’s future — perceiving it as an investment for their child’s academic career, despite giving medication being an unpleasant feeling for them. Thus, they constructed themselves as a ‘good parent’ which allowed them to resolve any feelings of guilt about giving medication.

For the adults with ADHD, taking medication was also about a responsibility to ‘fit in’ at work, within family and in relationships. They experienced improvement on everyday activities, organising tasks at work, interpersonal skills and having meaningful conversations like ‘normal people’. They found their family and friends coped better with them when they were on medication. As such it was their responsibility to fit in with family and society. As Susan, who was also taking medication for ADHD, reflected:

*I take my pill to cope with pressure ... I could cope with the world ... if I didn’t take the pill I wouldn’t be able to talk to you like this ... wouldn’t be able to focus at work ... my husband copes better with me when I am on the pill ... so I have to [take medication], to stay in the relationship, to keep our life easy.*

**Discussion**

The findings of this exploratory study assist in understanding the complexity of ADHD. The results consisted of interrelated yet sometimes contradictory themes that depicted the participants’ views of ADHD and stimulant treatment. There were three overarching themes: an impairment to achieving success, diagnosis as a relief and responsibility. The findings from this study reflect the ontological and epistemological assumptions of the social constructivist framework [35], which assumes that across individuals there may be multiple understandings of phenomena, being in this instance ADHD and attitudes towards its treatment with stimulant medication. It was notable that the themes were defined and redefined by the participants particularly through their everyday interactions with others in a community setting.

ADHD is perceived to be an impairment to achieving success reflected in two sub-themes: ‘it’s a double-edged sword’ and ‘it has to be fixed’. The expression ‘double-edged sword’ in this study furrows similarity to observations made in a UK study, where Singh et al. [36] noted that young people with ADHD expressed a dichotomous sense of themselves. They felt that their ADHD behaviour was ‘lack’ but then acknowledged that their fun behaviour was ‘annoying’ to others. The participants in this study perceived ADHD as fun, challenging and interesting; however, when comparing the fun behaviour with the perceived obstacle to achieving success, and particularly academic success, they chose to accept ADHD as an impairment which had to be ‘fixed’.

The participants had a biomedical understanding of ADHD, ascribed to it a causal relationship with academic under performance [37] and accepted stimulant medication as the eventual treatment of choice, albeit sometimes after seeking alternatives or as the mainstay of a broader treatment strategy. This was in line with a help-seeking behaviour model for ADHD, which suggests that the individual’s perceptions about ADHD influence their treatment choice [38]. Our findings resonate with those from Canada, where Johnston et al. [39] identified that people’s degree of acceptance of a medical aetiology of ADHD was significantly associated with stimulant treatment choices. The participants in this study were Caucasians, relatively affluent and well educated. Understanding ADHD as a medical condition and accepting stimulant treatment to improve academic performance is comparatively more common among Caucasian families than in other ethnic groups in the US and UK [6, 40]. However, when a child’s academic achievement seemed to be threatened by ADHD, people from other cultural and ethnic background were also found to accept stimulant treatment. Korean parents who tended to take personal responsibility for their child’s ADHD behaviour and had initial negative attitudes towards medication treatment, were reported to administer stimulants once they believed that ADHD was associated with their child’s relative lack of academic achievement [41]. In a study in India, the findings suggested that parents who resisted a biomedical explanation of their child’s ADHD behaviour tended at first to seek religious help to minimise the impact of the ADHD. The same parents, however, sought medical interventions when they perceived that problems with their child’s academic performance were not improving [42].

Participants in this study described a sense of relief following diagnosis, as it provided them with an explanation for the difficulties they or their child had experienced. The sense of relief stemmed from the fact that the diagnosis reassured them that the problem behaviour was not a personal failing in any moral sense, but rather a mental or at least cognitive disorder. In a phenomenological study of eight adults with ADHD in the UK, Young et al. [43] also reported that the diagnosis eliminated an individual’s sense of failure as their ADHD behaviour could be explained and attributed to a specific disorder. The parents in this study tended to defend themselves, saying that they did their best to be ‘good’ parents and so the parenting was not the cause of their child’s ADHD. As such, the diagnosis validated the child’s problem behaviour and school failure what not a reflection of failed parenting. These findings have
parallels in another study by Singh [46], conducted in the UK and US among 153 children and their parents, for whom the diagnosis provided a great relief. Parents (mothers especially) with an ADHD child often walk a fine line between perceiving themselves as 'good' and 'bad' parents, because they are most often blamed for their child's misbehaviour and under achievement [45–47]. Hence, scholars argue that although parents use the biomedical model of aetiology of ADHD to provide some relief from parental blame, the medical model may not serve to provide total relief from feelings of personal responsibility, stress, anxiety and guilt [44, 48]. An Taylor et al. [24] noted in an attempt to make the right decision for their child about the stimulant treatment, parents go through several stages in which they face contradictory societal attitudes, such as parental blame for their child's misbehaviour on one hand, while also experiencing anxiety and guilt feeling about drugging children by administering stimulants. To cope with the stresses of raising ADHD children and the associated societal pressures, parents tend to defend themselves by employing strategies like advocacy, education and strategic difference [49], all of which are congruent with the findings from this study.

Parental concern about the potential long-term side effects of stimulant medication was observed in another study in the US, where parents of children with ADHD expressed fears and accepted stimulant treatment reluctantly, even though they agreed that the medication helped their child [50]. Despite being worried about long-term effects and some immediate unpleasant side-effects of stimulant medication, parents in this study felt that it was their responsibility to continue with the medication to improve their child's self-esteem by helping the child feel normal and to 'fit in' with the community. Whilst results have been reported where parents discontinued stimulant treatment in their child's best interest due to uncertainty about long-term effects on brain function, related stigma and the child's dislike of use [51], the present findings are more consistent with those of Hansen and Hansen [48], who found that parents tolerated the medication's side effects and risks in the hope that it would play an important role in enabling the child to attain their academic goals and achieve success in their adult life.

Parental effort to improve their child's academic performance and boost self-esteem is a rational consequence of the fact that higher education is a critical path to one's career success in modern society [52, 53]. To achieve career success, an individual is required to develop competency across a wide range of personal qualities, which may include self-esteem [54, 55]. While some investigators have found no influence of self-esteem on relationship or career success [56, 57], others claim that a high level of self-esteem is crucial for success and life satisfaction in these spheres [58–60]. Whether one's self-esteem serves career success or not, self-esteem is valued in today's society [61], and developing children's self-esteem is reportedly evident as a cornerstone of contemporary Western parenting practices, particularly in middle class families [62]. In a qualitative study using semi-structured interviews with Canadian parents of children seen as cognitively impaired (including some with ADHD and learning disabilities) and those with unimpaired children, Ball and Wadding [22] found that parents would consider stimulant use if they perceived their child was struggling at school, failing to fit in or had low self-esteem. The parents in their study believed that it was their responsibility as good parents to make their child feel normal and encourage them to succeed in life.

The adults diagnosed with ADHD in this study also referred to their needs to feel 'normal', to have the ability to interact with other people, to belong in the community and to be accepted by family and friends. These findings are consistent with other studies where adults with ADHD perceived that being accepted by others as a normal, responsible social being was important [43, 63], and that the medication enabled a sense of normality and social belonging to occur [43, 64].

The findings from this study suggest that individuals' perceptions and experiences shared much in common in the general sense, yet in detail the individuals' journey had been diverse and complex. The findings underline that a person's understanding of ADHD behaviour and their attitude towards stimulant treatment are important considerations in selecting an appropriate intervention and in developing policy on the regulation of stimulant treatment use. Individuals who do not experience the perceptions of difficulties in academic performance or fitting in with society may not necessarily seek stimulant treatment even if it would be beneficial from an objective viewpoint. This was noted in the interview with Susan, who thought that her older son also had ADHD, but did not seek treatment for him because he was achieving school grades to her satisfaction. On the other hand, desire to accelerate academic performance may motivate individuals to pursue the non-medical use of stimulants [65, 66]. Parents were hesitant to use stimulant medication initially due to long-term side effects, but administered it as they were concerned about their child's academic under performance, self-esteem or failing to be 'normal'. Some parents may consider stimulant medication if they perceive these drugs as less harmful or if cultural trends redefine what is normal.

This study contributes to the body of literature with its focus on individuals' perceptions of ADHD and attitudes towards stimulant medication, including perceived roles of medication in child's future. Paying attention to perceptions
of ADHD and reasons for seeking or not seeking stimulant treatment is important when planning appropriate interventions for this condition to avoid over-diagnosis and overtreatment. The findings reinforce the need for more education of medical professionals to enable them to plan appropriate interventions and to give appropriate support and guidance to optimize outcomes for individuals with ADHD and their families.

There are some limitations to this study that deserve consideration. Firstly, the participants were white, middle-class people, living in a metropolitan area. As such, their perceptions may not reflect those of community members from other backgrounds, highlighting the need for research among culturally, ethnically and socioeconomically diverse groups in the future. Secondly, as the sample was largely female, the views of a wider range of males were somewhat absent from the research. Thirdly, three of the four adults with ADHD were parents who were diagnosed after their children had been diagnosed, and mostly described their experience as being parents. Even though the experience of one adult with no children was little different from the parents diagnosed with ADHD, findings drawn from this sample may not be transferable to the perceptions of ADHD and stimulant treatment of adults diagnosed with ADHD. Fourthly, given the nature of qualitative analysis, this study represents only one interpretation of the participants’ experiences, hence it delivers a partial, static picture of their perceptions of ADHD behaviour and attitudes towards stimulant treatment. Further, the analysis primarily denoted interpretations made by a single research group with the possibility that others might draw different inferences. Despite these limitations, this study does provide some important data with respect to the factors that shape individuals’ attitudes towards ADHD and influence individuals’ treatment choices. Building on these insights, further research can be conducted in a format that would canvass a wider range of views. Future research could also include a multi-perspective and longitudinal design, interviewing children, young adults and their parents to explore evolving perceptions of ADHD and medication over time.

Conclusion
The participants in this study perceived ADHD behaviour as an impairment to achieving success in life. A desire for academic achievement, good self-esteem, being normal and a sense of belongingness were important driving forces for stimulant treatment use among parents of children diagnosed with ADHD. Adults diagnosed with ADHD found stimulant medication was important for a responsible person to fit in to the community. The findings have potential to be used to raise awareness and understanding among medical practitioners working with ADHD adults, children and their parents of the perceived reasons why individuals seek or do not seek stimulant treatment.

Availability of data and materials
In accordance with the Human Research Ethics Committee, University of Western Australia (HREC-UWA) protocol, research data involving human participants cannot be made available to the public for confidentiality and ethical reasons. Demographic and interview questions are included as an additional file.

Additional file

Additional file 1: Demographic and Interview Questions. (DOCX 34 kb)

Abbreviations
ADHD: Attention Deficit Hyperactivity Disorder. UK: Western Australia.

Competing interests
The authors declare that they have no competing interests.

Authors’ contributions
MR and CSN participated in the study design and formulation of data analysis plan. MR carried out the data collection, data analysis of the study, and prepared the initial draft of the manuscript. CB was involved in the theoretical framework and helped in selecting findings. DR critically reviewed the manuscript for intellectual content. All authors reviewed the draft, contributed to the discussion and approved the final manuscript.

Acknowledgements
Manojit Ghosh was the recipient of the Australian Postgraduate Award (S190000879). We express our gratitude to all the participants who must remain anonymous.

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Received: 23 October 2015 Accepted: 12 April 2016
Published online: 22 April 2016

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