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Attention Deficit Hyperactivity Disorder: an Aboriginal perspective on diagnosis and intervention

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Attention Deficit Hyperactivity Disorder (ADHD) arising from a Western health model has generated much global debate about its relevance in Indigenous communities. More importantly, it has raised questions concerning acceptance of its diagnosis and intervention, hence affecting early identification and treatment compliance. The current study explored an Aboriginal perspective of diagnosis and treatment compliance of ADHD in an Australian Aboriginal community. Using a qualitative approach, 27 participants aged between 22 and 52 years from a Western Australian metropolitan Aboriginal community comprising community members, Aboriginal mental health and education professionals, and Aboriginal parents of children with ADHD, were interviewed either individually or in groups. Participants identified differences in child rearing practices, expectation of child behaviour in school, higher tolerance of hyperactive behaviour within the Aboriginal community and lack of information about ADHD as the main reasons for parents not seeking medical help for the child. Participants also saw the changes in a child's behaviour after medication as a loss of identity/self and this was reported to be the main contributor to treatment non-compliance. Overall, most participants recognised the detrimental effect of having ADHD. However, the current diagnostic process and treatment are not culturally appropriate to assist the Aboriginal community to effectively manage this disorder in their children.

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Keywords: Attention Deficit Hyperactivity Disorder, Australia, Aboriginal population

23 Attention Deficit Hyperactivity Disorder (ADHD) is a clin-24 ically diagnosed disorder (APA, 2013) defined by ageinappropriate levels of inattention, hyperactivity or impul-25 26 siveness that cause impairment in all areas of life (Castle 27 et al., 2007). The impairment is life-long in approximately 28 30% of the cases, with increased rates of comorbid mental 29 health disorders and disability (Mannuzza, et al., 1998). 30 The world-wide prevalence rate of ADHD among chil-31 dren/adolescence and adults stands at 5.29% (Polanczyk, 32 Lima et al., 2007) and 4.4% (Polanczyk and Rohde, 2007) 33 respectively. In Australia, the ADHD prevalence rate was estimated to be at 7.5% among mainstream Australian chil-34 35 dren (Graetz et al., 2001). Among the mental disorders in children between six and fourteen years old, the Australian 36 37 Institute of Health and Welfare (2008a) reported a preva-38 lence rate of 13% for ADHD as compared to 3% for depressive disorder. In reviewing their educational needs, the 39 Australian Institute of Health and Welfare (2008b) also re-40 ported that 77% of the children with ADHD in the five 41

to nineteen-year-old age group experienced schooling restrictions and half of them required special assistance with learning.

ADHD is a serious disorder with negative life-long consequences and its correct identification and classification are critical, particularly in the Aboriginal population. In the 2012/2013 annual report from Department of Corrective Services Western Australia (WA), it is noted that while Aboriginal people are estimated to make up only 3% of the WA general population, they also made up around 40% of the adult prison population and 60% of the juvenile detention population. Moore et al. (2013) reported an elevated prevalence of ADHD in correctional facilities in the state of New South Wales in Australia. Given that one third of the

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56 participants reported by Moore et al. were identified as Abo-57 riginal or Torres Strait Islander, such finding suggest that ADHD may be an important factor to consider in relation 58 59 to the incarceration of Aboriginal and Torres Strait Islander people. Further support came from a study examining men-60 tal health problems among Aboriginal children in Western 61 Australia (Zubrick et al., 2005). Zubrick et al. found that the 62 risk of experiencing hyperactivity problems for Aboriginal 63 children stood at 15.8% while for non-Aboriginal children 64 65 the risk was at 9.7%. They also reported that this risk was the highest in metropolitan areas as opposed to rural regions. 66

Like many other mental health disorders, identifying 67 ADHD is a challenge. There are no visible biomarkers avail-68 69 able to indicate the presence of the disorder and diagnosis is made solely based on the interpretation of behaviours. This 70 challenge is more pronounced in a non-Western culture, 71 72 and there is ongoing debate as to whether ADHD is a cul-73 tural construct (e.g., Timimi & Taylor, 2003). The concept 74 of ADHD and its interpretation of normal and pathological 75 behaviours stem from a Western perspective, and cultural 76 factors are largely ignored in its diagnostic methodology. 77 However, a systematic review and meta-regression analysis 78 of over 300 articles from all world regions failed to find any evidence that ADHD is a culturally based construct 79 80 (Polanczyk et al., 2007).

81 For Aboriginal people, many aspects of Aboriginal life such as the land, kinship obligation and religion are in-82 terconnected with health (Elkin, 1994). Hence health, for 83 the Australian Aboriginal people, is viewed in terms of har-84 85 monised interrelations between spiritual, environmental, ideological, political, social, economic, mental and physical 86 domains (Zubrick et al., 2005). It is this interconnected-87 ness between the different domains that helps to provide 88 the explanatory model for the cause of the ill health for 89 90 Indigenous Australians (Maher, 1999). Such a worldview 91 on health was considered responsible for the disparity in 92 understanding the symptomology of the mental disorder 93 between the mainstream community and Australian Abo-94 riginal communities in the Kimberley and urban Perth areas 95 of Western Australia (Vicary & Westerman, 2004). How-96 ever, it is through this understanding of the Indigenous descriptions and perceptions of mental health that a two-way 97 98 understanding between Indigenous peoples' construct of wellness and Western biomedical diagnostic labels and their 99 treatment pathways can be established (Ypinazar, Margo-100 101 lis, Haswell-Elkins & Tsey, 2007). Therefore, understanding this difference and how health issues are explained are 102 103 necessary steps in assisting the interaction between Western health professionals and Aboriginal peoples (Maher, 104 105 1999).

106A number of authors have emphasised the importance107of incorporating a cultural framework in diagnosing psy-108chiatric disorders (e.g., Alarcon, 2009; Dingwall & Cairney,1092010; Hunter, 2007; Jiloha, Kandpal & Mudgal, 2012; Loh110et al., 2016; Maher, 1999; Vicary & Westerman, 2004). The111establishment of the social and emotional wellbeing (SEWB)

health framework in Australia was a result of this recogni-112 tion (Kowal, Gunthrope, & Baili, 2007; Zubrick et al., 2005). 113 Likewise, to some extent, the widely used DSM-IV, the latest 114 DSM-V and the ICD-10 classification for psychiatric disor-115 ders have also emphasised such an approach, focusing on 116 understanding the strong cultural biases that may influence 117 the understanding of certain behaviours (Alarcon, 2009). 118 However, a cultural framework is lacking in the diagnosis of 119 ADHD and only Western oriented behaviours are used in 120 helping to identify inattention, hyperactivity and impulsiv-121 ity. This presents an issue in diagnosing ADHD as different 122 cultures have different definitions of what constitutes nor-123 mal or abnormal expressions of behaviour (Ardila, 1996). 124 In addition, different symptomatology may be expressed 125 for the same psychiatric disorder (Thomas, Cairney, Gun-126 thrope, Paradies & Sayers, 2010). Hence, the diagnostic ap-127 proach to ADHD should include not only the presence of 128 behavioural symptoms, but also should recognise and in-129 tegrate the person's cultural beliefs in the diagnosis. The 130 current diagnostic approach for ADHD therefore raises the 131 issue of cultural sensitivity and appropriateness for the Abo-132 riginal community. 133

Cultural sensitivity and appropriateness not only impact 134 on diagnosis but can also result in deterring help seeking 135 behaviour and treatment compliance. Overall, mental ill 136 health ranks second in its contribution to the total dis-137 ease burden for Indigenous Australians (Vos, Barker, Stan-138 ley & Lopez, 2007). Burdekin (1994) reported that mental 139 illness among Aboriginal and Torres Strait Islander peo-140 ples is a common and crippling problem and often they 141 are undiagnosed, unnoticed and untreated. The rate of In-142 digenous adults experiencing high to very high levels of 143 psychological distress was reported to be more than dou-144 ble compared to that of non-Indigenous Australians (Aus-145 tralian Bureau of Statistics, 2006). However, only less than 146 one third of Indigenous people were reported to access 147 any form of mental health service (Slade et al., 2007). The 148 under-usage of mental health services may reflect the cul-149 tural differences in how mental health problems are un-150 derstood, experienced and reported by Indigenous people 151 (Dobia & O'Rourke, 2011). By extension, this low rate of 152 accessing mental health services among Indigenous Aus-153 tralians also raised the question of acceptance of Western-154 based diagnoses by the Australian Indigenous community. 155 Such a disparity in worldviews about mental health beliefs 156 that exist between the two cultures may also influence the 157 early detection and help-seeking behaviour of Indigenous 158 Australians. 159

Another issue relating to diagnosis is treatment intervention. Making an accurate diagnosis of ADHD, but failing to follow through with the treatment intervention will not be helpful for the individual affected by the disorder. Any effective intervention requires it to be culturally attuned to the people to whom it is being offered (Carey, 2013). Among Indigenous Australians, the cultural sensitivity of interventions is especially important (Hunter, 2007). Mental health

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168 programmes developed within the individual communi-169 ties have to ensure that interventions are appropriate and meaningful to the local culture. The involvement of the 170 171 local community members is critical to its success. It has been shown that resources will be well accepted if they are 172developed or contributed to by Indigenous people (Camp-173 bell, Pyett, McCarthy, Whiteside, & Tsey, 2007). Moreover, 174 culturally sensitive delivery and location of services have 175 also been found to be important factors for achieving ef-176 177 fective intervention. A successful example is the Aboriginal youth mental health partnership programme that provides 178 179 accessible and culturally appropriate mental health services for Indigenous youth involved or at risk of involvement in 180 181 the juvenile justice system. Over a three-year period, the metropolitan Child and Adolescent Mental Health Services 182 (CAMHS) saw an increase of 44.6% in service usage by the 183 184 youths and their families, and an increase in 117% in the number of Indigenous youth receiving a service from the 185 186 Country Services (Dobson & Darling, 2003). This increase 187 in the rate of service usage suggests that incorporating a 188 culturally appropriate mental health programme led to an increase in the willingness of the youths and their families 189 to utilise the services. In recognition of the importance of 190 191 cultural sensitivity, a national Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004-2009 192 193 was set up by the Australian Health Ministers' Advisory Council to guide services and practitioners working with 194 Aboriginal and Torres Strait Islander peoples. Despite such 195 development, setting up and implementing such culturally 196 197 appropriate mental health services is not widespread nationwide and it remains an ongoing challenge in the Aus-198 tralian mental healthcare system (Walker, Schultz & Sonn, 199 200 2014).

201 Like many developed countries such as the United States 202 and the United Kingdom, Australia faces issues with limited healthcare funding and resources. At the same time, 203 204 government reports and healthcare research focusing on In-205 digenous health have emphasised that current mental health 206 services are not adequately addressing the mental health is-207 sues experienced by the Aboriginal community. To address 208 these constraints, it is vital that healthcare funding and resources allocated to Aboriginal mental health services are 209 210 used to provide effective programmes that can meet the 211 needs of the Aboriginal community and ensure that programmes will be well utilised. To ensure such an outcome in 212 213 relation to ADHD, the logical initial step would be to understand the Aboriginal worldview of the concept of ADHD. 214 215 Such data could then be used to inform the development of 216 an effective diagnostic and intervention programme that is 217 culturally appropriate and relevant for Aboriginal children 218 with ADHD. Hence, the current study aimed to examine 219 how people from the Aboriginal community explain the 220 Western concept of ADHD and its symptomatology, and their approach to managing these ADHD symptoms. This 221 222 study adopted a qualitative approach using a reiterative pro-223 cess of data collection.

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Method

Research design

The present study employed a qualitative research design, in order to gain an in-depth understanding of the participants' experiences and understanding of ADHD. A phenomenological methodology using a combination of in-depth, oneon-one interviews and focus groups containing no more than five participants per session was used to gain insight into the participant's understanding of ADHD. These interviews were transcribed with a thematic analysis employed as the chosen method of qualitative investigation.

Participants

The present study included a purposive sample of 27 Australian Aboriginal participants, given that the objective of the present study was to obtain an Indigenous Australian perspective of ADHD. Participants ranged from 22 to 52 years of age and comprised 19 females (mean age = 39.1 years), and eight males (mean age = 41.0 years). Level of education varied from completion of eighth grade to completion of tertiary (university) education. All participants reported having children of their own. Five participants were either the parent or grandparent of a child with ADHD; eight participants knew someone with ADHD. In order to meet eligibility criteria, participants were required to be aged 18 years and above, and free of any neurodevelopmental or psychiatric orders that would interfere with their ability to provide informed consent.

A snowball method of recruitment was adopted in this study where participants were recruited through word of mouth. The recruitment process began with the Aboriginal Cultural consultant making contact with the Aboriginal community in Perth, Western Australia, through Aboriginal agencies and individual Aboriginal community members who acted as contacts for the community. All participants were located within the metropolitan area of Perth, Western Australia, at the time of the study; however it became evident during the interview process that a substantial proportion of these participants had also lived in rural and other urban parts of Australia.

Procedure

Ethics approval was obtained from the University's Human 264 Research and Ethics Committee and the Western Australian 265 Aboriginal Health and Ethics Committee. Prior to recruit-266 ment of participants, an Aboriginal reference group com-267 prising four Aboriginal academics, two Aboriginal health 268 professionals, and one Aboriginal community member was 269 established. The six members that comprised this reference 270 group were also active members of Western Australia's Abo-271 riginal community. The purpose of this reference group was 272 to work closely with the individuals involved in the recruit-273 ment and interview process, to guide the present study in 274 a manner that upheld cultural sensitivity and appropriate-275 ness for prospective participants, and to assist in the valida-276 tion of research methods and findings. In addition to this 277

six-member reference group, a male Aboriginal consultant
(second author) provided further expertise and assistance
with the recruitment and interview process, and interpretation of the data.

282 Information sheets were provided to Aboriginal agencies within the Perth metropolitan area for distribution 283 among peers. Prospective participants were able to obtain 284 further information through contact with the researcher, the 285 Aboriginal consultant, or through the agency from which 286 the information sheet was provided. A second recruitment 287 method was through presentations at Aboriginal centres to 288 disseminate information and answer any questions about 289 the study. Information provided in the information sheet 290 presented descriptions of behaviours or difficulties associ-291 ated with ADHD symptomatology such as poor concentra-292 tion and over-activity, without mentioning the terminology 293 "ADHD". Prospective participants were also informed that 294 295 the study was aiming to understand any cultural differences 296 in managing these behaviours. Recruited participants could 297 choose to be interviewed individually or in a group, at their 298 discretion.

299 All participants were provided with an information sheet 300 detailing the purpose of the study, the extent of their involvement and their right to withdraw. Any outstanding 301 302 queries or comments held by participants were answered prior to giving their informed consent to take part in the 303 304 present study. A debriefing session with the principal researcher and Aboriginal consultant was also made available 305 306 to participants, should they have any comments or issues 307 following the study.

Interviews were scheduled at a time and place that was 308 convenient and comfortable to participants. In both the 309 individual and focus group interviews, the issues of confi-310 dentiality were discussed. In addition, participants in focus 311 312 groups were informed that anonymity of participants was 313 not possible within the group. All interviews were audio recorded for the purpose of transcription. Once data were 314 transcribed and validated by participants, all audio record-315 ings were destroyed. All transcribed data were de-identified 316 317 in order to ensure the anonymity of participants.

318 The data collection phase of the study comprised two stages. The first stage involved the semi-structured inter-319 320 view process (either individually, or in groups). Interview sessions with no more than two participants lasted for ap-321 322 proximately one hour, where the larger focus group sessions 323 ranged from 90 to 180 minutes. In total, the present study included five individual interviews and seven interviews in-324 volving more than one participant at a time. Data collection 325 ceased when saturation was achieved. The second stage of 326 the study involved the validation of initial themes by par-327 328 ticipants in order to ensure the accuracy of information. 329 This was done by providing participants with the interview transcripts; any information deemed as inaccurate by 330 participants was amended to their satisfaction. Data were 331 then thematically analysed in order to identify the promi-332 333 nent themes pertaining to the present research question, which was to obtain an Indigenous Australian perspective334of ADHD. Participants were informed that they could re-
quest a copy of the findings upon study completion.335

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Data analysis

Data were thematically analysed using version 10.0 of qual-338 itative analysis program, NVIVO. Thematic analysis was 339 selected as the most appropriate method for analysing the 340 information obtained through the interviews in the present 341 study. Thematic analysis reflects the participant's own point 342 of view, descriptions of experiences, beliefs and perception 343 of a phenomenon (Luborsky, 1994); in the present study, it 344 pertains to ADHD. Resonating with all types of qualitative 345 analysis, the purpose of thematic analysis is to identify the 346 lived experiences and meanings of participants. This process 347 is particularly beneficial within the context of Indigenous 348 populations; thematic analysis is able to give a 'voice' to the 349 minority populations whose opinions are usually silenced 350 (Benoit, Carroll & Chaudhry, 2003). 351

Results and discussion

The questions formulated for the semi-structured interview 353 broadly focused on (1) typical child behaviour in school, 354 in community and at home; (2) any gender differences in 355 child behaviour; (3) behaviour that suggests possible prob-356 lems in a child and its negative impact, focusing on ADHD 357 symptoms; (4) belief system around the Western concept of 358 ADHD, the symptoms, diagnosis and treatment; (5) man-359 agement of a child with ADHD or having ADHD-like symp-360 toms in the Aboriginal community; (6) any knowledge of 361 and/or experiences with health services or agencies that as-362 sist with Aboriginal children diagnosed with ADHD; and 363 (7) existing resources and healthcare practices meeting the 364 needs of Aboriginal families and children diagnosed with 365 ADHD or having ADHD-like symptoms. Thematic anal-366 ysis identified several prominent themes (some with sub-367 themes) that emerged as commonly discussed topics among 368 the 12 interviews that were conducted. 369

Hyperactive behaviour

The first theme identified in the interviews related to hy-371 peractive behaviour. It is important to note that this hyper-372 active behaviour included, but was not limited to, ADHD. 373 Participants shared their experiences, understanding, and 374 interactions with ADHD. Responses were varied, as some 375 participants had direct contact with family members with 376 ADHD, while others were aware of members in their com-377 munity who had the disorder (for example, they knew of 378 people whose children have ADHD). All participants were 379 aware (to varying degrees) that ADHD is typified by hy-380 peractive behaviour; therefore many participants provided 381 a focus on broader hyperactivity, rather than specific to 382 ADHD. Two prominent sub-themes were identified. 383

Hyperactive behaviour is problematic. Hyperactive behaviour was seen by all participants to be problematic and 385 386 undesirable in a number of circumstances. This hyperactive 387 behaviour was recognised to be problematic in a variety of domains. This included at home, at school, and in public 388 389 (e.g. shopping). For example, "My daughter just likes everything all at once and she just goes from one toy to the other 390 and pulls out all her clothes and then goes to the kitchen and 391 pulls out all the food and then tips out all the milk, and while 392 I'm trying to clean that up she is already in her room doing 393 something else or trying to get into [sister]'s room, putting 394 all the washing powder on the floor and stuff like that". This 395 problematic behaviour not only affects the individual with 396 ADHD but also affects those around the individual. Some 397 of the parents reported that they implemented strategies 398 399 such as going shopping while their children were at school so as to avoid allowing their children to display hyperactive 400 behaviour in public. 401

Participants generally agreed that this hyperactive be-402 403 haviour has implications in many domains or areas rele-404 vant to the child. Understanding such implications is best 405 achieved using an ecological systems perspective such as 406 Bronfenbrenner's ecological theory of development which identifies five environmental systems or domains crucial to 407 the individual (Bronfenbrenner, 1992). In particular, the 408 microsystem identifies peers, school and family, all of which 409 were reported by participants to be impacted negatively by 410 411 the child's hyperactive behaviour. On an individual level, the child's hyperactive behaviour was reported to impact 412 on his/her ability to concentrate and learn. Several partici-413 pants were caregivers of children with ADHD and provided 414 415 invaluable insight into the negative implications on wellbeing of the caregiver as a result of the child's hyperactive 416 behaviour. For example, "Sometimes there is conflict between 417 me and my fourteen year old, or me and my eleven year old, 418 because of their condition. And it stresses me out to the max, 419 420 where I can't put up with it". Some participants also disclosed 421 secondary stressors as a result of the child's hyperactive behaviour in public settings, such as feelings of judgment; 422 423 parents of hyperactive children felt that their child's behaviour was a reflection on their parenting ability, "I'm sick 424 of people trying to judge... you don't have to look after my 425 426 child". Hyperactive behaviour was also associated with externalising behaviours such as aggression and destructive 427 428 behaviours. Several participants reported that the hyperac-429 tive child would get into both verbal and physical conflicts with other children, teachers and caregivers, or would cause 430 431 damage to property, "Well, when they get angry, they punch a hole in the door, and verbally abuse, swearing at one another". 432 433 This subtheme reflects the general consensus among participants, which was that hyperactive behaviour is prob-434 435 lematic, and these problems extend beyond the hyperactive

436 individual and to those surrounding them as well.

437 Desired behaviour. The second subtheme within the do438 main of hyperactive behaviour related to desired behaviour,
439 or how participants believed children with hyperactive be440 haviour should be acting. Participants recognised the as-

sociation between the presence of hyperactive behaviours, 441 reduced capacity to concentrate and learn and disruption to 442 others. Hence, they expressed a general desire for a reduction 443 in these children's hyperactive behaviours in school. Asso-444 ciated with this theme is a frequently occurring subtheme, 445 that of the concept of "respect". Participants frequently used 446 the term respect to explain the types of behaviours that 447 are desirable. To the participants, reducing hyperactive be-448 haviours was desirable but many also recognised that chil-449 dren should not be sedentary and should live active lives, 450 "And it is, it is being kids but being respectful while being 451 kids, doing what kids should be doing". Participants generally 452 agreed that certain behaviours were required in certain situ-453 ations, and although children should be active and play, this 454 behaviour is not suitable in different circumstances. This 455 subtheme reflects the general belief that children should be 456 able to know, for example, that different behaviour is re-457 quired for concentrating in class, as opposed to playing in 458 the playground. At all times, the child should demonstrate 459 respect for self and for others. Other examples of participant 460 statements related to the theme of 'Hyperactive Behaviour' 461 are provided in Figure 1. 462

ADHD

The second theme emerging from the interviews was related to perceptions of ADHD. With the exception of two participants, ADHD was widely recognised to be a real mental disorder, although participants often disclosed that they were unsure what the exact causes were. This consensus is best summarised by one participant's statement, "*I think it is a genuine condition because, you know, like you see it. And not all kids present with it. So, it is just a handful of them that might present with it, so you know there is something going on there but you really don't know what*". Within this theme, three distinct sub-themes emerged.

Typical ADHD behaviours. When discussing ADHD 475 specifically, participants often reported the symptoms that 476 were indicative of a disorder. This subtheme shared some 477 overlap with the previous theme regarding hyperactive be-478 haviour; however, participant responses to this present sub-479 theme were used to describe symptoms of ADHD specif-480 ically, as opposed to hyperactivity in general. Within this 481 subtheme, ADHD was most commonly thought to manifest 482 primarily in terms of hyperactive behaviours ("He couldn't 483 sit down. He was climbing on the roof of the school, throwing 484 chairs around, and all that stuff, you know, very aggressive, 485 you know; especially when he wasn't on his medication"), but 486 also within the context of inattentiveness ("... their minds 487 still keep ticking over and it is like they are still trying to do 488 more than one thing at a time. They can't just do one thing... 489 they are still thinking about the show that they were doing this 490 morning or what they are going to do next and stuff like that 491 instead of just focusing on the one thing"). The participant's 492 perceptions of what typical ADHD behaviours were (i.e., 493 restlessness and inattentiveness) resonate with the nosolog-494 ical classification symptoms of the disorder. Hyperactivity 495

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FIGURE 1

Examples of responses indicative of the theme of hyperactive behaviour

496 was more frequently mentioned than inattentiveness, which
497 could be attributed to the consequences of hyperactivity be498 ing more easily noticed than inattention.

499 Causes of ADHD. As previously mentioned, a general consensus among nearly all participants was that ADHD 500 501 was understood to be a legitimate disorder; participants frequently provided insight into what they believe causes 502 503 ADHD. The most frequently cited cause of ADHD, as dis-504 cussed by the participants, was attributed to diet. The sugar, 505 preservatives and additives in food were widely perceived 506 by participants to contribute to ADHD. One participant 507 elaborated on this commonly held belief, emphasising the 508 cultural differences between a traditional Indigenous diet and non-Indigenous diet; "And really like we have a much 509 510 shorter span of time for our bodies to adapt and change to that compared to other societies, because they have had those diets 511 512 for a lot longer. So it makes you wonder what it does to our bodies, you know. Like, diabetes is a huge one. So maybe it is 513 514 a similar thing". The notion that diet was a primary factor 515 in the formation of ADHD was also reinforced by several 516 participants who reported marked changes in hyperactive 517 children after their diets were modified, "... he was on medication and then we stopped the medication and started the 518 fresh diet, and that really helped him". 519

Participants also attributed the role of environmental
factors in ADHD ("... *it is up to the environment and the parenting and the caregivers that are there. If those parents are not focused on the kids, well then they are going to be diagnosed because the kid will just keep acting out*..."). Some participants provided further insight into what they believed were
the causes of ADHD, recognising the interaction between

biological and environmental factors, "I think there would 527 be a number of things. Maybe certainly environmental, maybe 528 there is some sort of chemical, not imbalance, but, you know, 529 environmental, physical, emotional, you know, there are things 530 maybe happening in the family or the environment that the 531 child is in, and also too I think there are kids probably being 532 misunderstood. So it might be a kid that say is really bright, 533 but the school can't give them what they need so they are sort of 534 acting up, so they are therefore seen as naughty and whatever 535 and the next minute they are diagnosed as that ... if you go 536 back into the family and you can see where the root problem 537 comes from ... ". 538

Attitudes towards treatment. Discussion on the treat-539 ment of ADHD resulted in a range of views by the par-540 ticipants. The most frequent mode of treatment discussed 541 by the participants was that of medical treatment (e.g. taking 542 dexamphetamine or Ritalin). Some participants expressed 543 positive outcomes as a result of medical treatment ("No word 544 of a lie, ever since he has been on his medication, his school 545 work is up"). However, most participants expressed nega-546 tive experiences with medication. Participants were gener-547 ally hesitant or doubtful in using medication as a means 548 of treatment for children with ADHD ("I think medication 549 should only be used as a last resort, as a very last resort"); par-550 ticipants believed that medication drastically reduced the 551 energy level of these children so that they would not be dis-552 ruptive in class, but this effect compromised their wellbeing. 553 "... they were saying that they didn't want their child to go on 554 the medication because it made them drowsy and they were 555 just zombied out. In the classroom they would just sit there 556 and you couldn't really get a lot of feedback". As a result, most 557



FIGURE 2 Examples of responses indicative of the theme of ADHD

558 participants did not support a pharmacological approach unless it was supported by non-medical treatments "No, I 559 would rather see that, say if it was my child diagnosed as that, 560 561 there would have to be a balance of medication and some therapy as a program. You know, yeah, medication is not just the 562 answer. We have got to look at the whole thing around that 563 child that can support it". Participants recognised the need to 564 treat ADHD, but believed that medication is an insufficient 565 566 strategy to address this issue.

Figure 2 provides additional statements made by partic-ipants related to the theme of ADHD.

569 Experiences with current services

- 570 The access to current services related to diagnosis and treat-571 ment of ADHD was explored with the participants. In gen-
- 572 eral, participants' experiences with the current available ser-

vices were negative. Three sub-themes within this theme were identified.

Current services are culturally inappropriate. Those in-575 terviewed provided valuable insight into the diverse cul-576 tural beliefs of Indigenous Australian people, compared to 577 non-Indigenous Australians. Several of these cultural differ-578 ences were important in understanding how current services 579 were inappropriate for Indigenous Australian children with 580 ADHD. One participant provided an example of how the 581 cultural difference may have implications for ADHD. "It 582 needs to be more visual for Aboriginal kids because they are 583 very, very visual kids. A lot of our kids that sat NAPLAN, 584 there is one particular boy, he is so knowledgeable in here, 585 he is brilliant, but he cannot put it down to paper. He can-586 not write it, but he can give you the answers if you actu-587 ally read it out to him, and that is another thing that the 588

589 Department needs to look at because the marking needs to 590 be done differently". Participants raised concerns about the 591 use of Western-based standardised testing on Aboriginal 592 children. They questioned if this would disadvantage Indigenous Australian children given that the assessments are 593 developed within a non-Indigenous framework. As a result, 594 Indigenous children may not be demonstrating their actual 595 596 capabilities because of this cultural bias.

The Western understanding of mental illness was also 597 598 implicated to be detrimental to Indigenous Australian children; "... you get the school psychs and they are white focused 599 and, yeah, it is very difficult". This has implications for the 600 601 entire school environment, as was recognised by several par-602 ticipants; "... they [Indigenous Australian children] are very verbal, because they want to have a yarn with one another. 603 They want to talk to each other, but you are not allowed to do 604 605 that because this is the way the classroom is set up. There is a time when you can talk and there is a time when you can't". 606 607 This subtheme, in conjunction with the previously discussed 608 'Attitudes towards treatment' subtheme contributed to par-609 ticipants' beliefs that a culturally appropriate intervention 610 should be implemented.

Need for culturally appropriate treatment. Participants 611 often expressed a need for intervention programmes that 612 613 recognised the differences in cultural needs for Indigenous Australian children. One participant had described the in-614 effectiveness of the current "one-size fits all" approach to 615 treatment of ADHD; "There are all different types of people 616 out in the community and they are all trying to make it be like 617 618 one. There is A, B, C and D, and they are all trying to make it look like Z. There needs to be certain services for certain people". 619 While most participants indicated a need for such programs 620 621 ("I think my personal opinion is that if you have got plenty of 622 Aboriginal kids in a region that have got ADHD you need to 623 have special programs in place for them"), other participants provided advice on how these programmes should be devel-624 625 oped. For example, one participant proposed a checklist of questions that the participant believed would be necessary 626 627 to facilitate an effective service; "So, in terms of its location, is it in a place where Aboriginal people would go? It is no good 628 629 having a facility, you know, where Aboriginal people won't be able to go to. Is it welcoming when people come in? Are the 630 631 staff that are working there, are they getting trained in Abo-632 riginal culture? Have they got connections with the Aboriginal 633 community that they are working in? Are there partnerships with Aboriginal organisations?" Given the strong family val-634 ues embedded within the Indigenous Australian culture, the 635 wider family should be an important target to maximise the 636 637 effectiveness of treatment; "Again, therapy, you need to have therapy where you help the whole family. You can't just fix the 638 child up. You know, you might have five kids and only one kid 639 has got AHDH or ADHD. They might have that one child, but 640 you got to end up that you got to fix up the whole family to help 641 642 the brothers and sisters understand why this one kid is carrying 643 on the way they are carrying on, help the mum and the nanna

and whoever is living in the house to understand and think,644'Well, okay, something is wrong with this child. They are not645just naughty. There is something really medically wrong with646them, because it has been after test, after test, after test.647statement reflects the general beliefs of participants, where648a need for culturally sensitive intervention was implicated.649

Other participants suggested ways in which the cultural 650 appropriateness of current treatments could be modified, 651 for example, "I think if you haven't got any trained Aboriginal 652 person then a non-Aboriginal trained person going with an 653 Aboriginal person into that home. So then you are breaking 654 down that barrier because they will feel safe if there is one 655 of their own kind, if you like, as well as a professional there 656 working with them", and "... if there is a non-Aboriginal 657 person going in there a lot of them will just - - The whole family 658 will sometimes clam up and say, 'Oh, you know.' They will 659 listen to you but when you go away they might be thinking, 'No, 660 I am not going to go with that one', whereas if an Aboriginal 661 person is present and said, 'Look, we are going to help you 662 and this is what we can do with you and work with your 663 family' I think they would be much more accepted than a 664 non-Aboriginal. Because, I don't know what it is, but they just 665 relate better to their own". 666

The information pertaining to this present subsection that was acquired through the interview process has important ramifications to inform future policy and practice; improving the cultural sensitivity of existing programmes, or tailoring new programmes that are tailored to the specific needs of Indigenous Australian children will increase the effectiveness of engagement and treatment.

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Lack of information. "Like I said, I have got a diabetes 674 educator. Why can't there be an ADHD educator?" When 675 discussing the availability of resources about ADHD, par-676 ticipants identified a considerable lack of information, per-677 petuating the problems related to the diagnosis and inter-678 vention treatment due to an individual's limited knowledge 679 of the disorder. Participants suggested that, rather than a 680 disorder, the child's hyperactivity could be perceived as mis-681 chievous behaviour. The lack of information extends beyond 682 disorder-specific information, and also into a lack of infor-683 mation pertaining to where help can be sought. This is best 684 exemplified by the following quote "A lot of Aboriginal peo-685 ple probably wouldn't know about mainstream services that 686 could probably help. They probably think like the health clinic 687 or the AMSs are the ones that would be able to help, so it is a 688 lack of awareness or knowledge about what is there . . . where 689 they can go for help apart from those ones". A desire for more 690 information was also expressed, for example, "But that is 691 like ADHD. We don't understand it. We know it is a sickness 692 and we know it can make you feel bad and that, but we don't 693 understand it. We need more educating about it", or "Therapy, 694 yeah, like, to talk to the parents because the parents don't know 695 what it is. You know, maybe the nurse would be able to tell the 696 parents how that child is feeling, you know, because to hold a 697 sick child all the time is very, you know, like, you are holding the 698



FIGURE 3

Examples of responses indicative of the theme Experiences with Current Services

*This additional subtheme is also informed by the "Attitudes Towards Treatment" subtheme described in Figure 2.

child but you just want them to get better, and you need that
knowledge from the research and for people to put it down for
Noongar people in plain English so they can understand". Access to information specifically about the disorder, but also
about what agencies exist to provide information on the

disorder was regarded as important amongst participants.

705 Limited resources. As well as a lack of resources, access to facilities providing assessment and treatment of ADHD 706 707 was also identified as an issue. There were several issues highlighted by participants. For example, participants re-708 ported difficulty in obtaining consultation with appropriate 709 healthcare professionals. This is best exemplified by one par-710 711 ticipant's experience, stating "There is a 15-month waiting list, and he starts school next year". This statement illustrates 712 713 how current services are ineffective in being able to meet 714 the demand for treatment. This waiting-list alone can be 715 detrimental to the child who was being discussed. Despite needing this treatment prior to school commencing, the 716 child will have to go through the first year of schooling 717 without this, placing the child at a disadvantage in later 718 719 years. This is further supported by another participant's experience, who advocated for the need for early intervention 720 721 in order to prevent more costly treatments later in life "... it 722 cost her \$5,000 to be able to teach him what they should have 723 done back in year 1 when he couldn't read and write . . . he just 724 could not get it, and my mum pushed and pushed and no one 725 listened". The location of certain professionals/treatments, and cost were also commonly cited as additional issues that726are barriers to treatment for ADHD.727

Additional comments related to this theme are provided 728 in Figure 3. 729

Conclusion

Through discussion within the community, we were able 731 to investigate ADHD from an Aboriginal perspective and 732 thus have a better understanding of the issues involved in 733 the assessment and treatment of this disorder in the Abo-734 riginal community. Most participants in this study agreed 735 that ADHD is a bona fide mental disorder as opposed to a 736 cultural construct. They believe that ADHD has a biological 737 or neurological origin, and that intervention is necessary to 738 address this disorder. Such a finding is in line with studies 739 conducted by Azevedo, Caixeta, Andrade and Bordin (2010) 740 and Azevedo and Caixeta (2009) examining a similar issue in 741 the Amazon Indigenous communities. These findings sug-742 gest that Aboriginal culture is no different from the Western 743 culture in viewing ADHD symptoms. The inability to self-744 regulate one's behaviour and to focus on task when the 745 situation warrants are problematic for both cultures. How-746 ever, the main difference between the two cultures lies in the 747 approach to address these symptoms. 748

Participants clearly support the notion that current treat-749ment approaches may be inappropriate for the Aboriginal750community, and that successful treatment rests on designing751

752 a more culturally appropriate assessment and intervention 753 for Aboriginal children with ADHD. In addition, a lack of 754 information about ADHD, the presence of culturally biased 755 assessment, and culturally inappropriate facilities and treatment were flagged. These factors appear to be impacting 756 on early identification, treatment and retention. Even when 757 parents and the child were on board with treatment initially, 758 compliance with treatment was short lived. When concerns 759 for accurate diagnosis, side effects of medication, and that 760 cultural self and identity appeared to be compromised in 761 the treatment process, attrition from treatment occurred. 762 Hence, it seems a sensible approach to incorporate cultural 763 sensitivity and appropriateness into the ADHD assessment 764 and treatment programme in ensuring that Aboriginal chil-765 dren affected by ADHD are receiving effective treatment. 766

With such findings revealed, it should be noted that the 767 sample only included participants residing in Perth and that 768 769 more than half of the participants have had direct contact 770 with someone with ADHD prior to their participation in 771 the study. The exposure to urban living and having prior 772 experience with ADHD may likely have rendered them to 773 be more accepting of Western concepts of disorders. Hence, 774 the sample is not representative of the wider Aboriginal communities in Australia. The views elicited from these par-775 776 ticipants only represent a subset of the Aboriginal people in 777 Western Australia. Moreover, only one community within 778 the Australian Indigenous population was involved in this study. Further research is needed to determine whether sim-779 780 ilar views in assessment and treatment of ADHD are held 781 by other Indigenous communities both within Australia and overseas. In addition, some of the ADHD symptomatology 782 such as hyperactivity and impulsivity can also be noted in 783 other psychiatric disorders such as bipolar disorder. In this 784 case, although both disorders present different distinctive 785 786 features in symptomatology, age onset and course of development, the overlapping symptomatology is likely to raise 787 question about misdiagnosis between ADHD and bipolar 788 disorder within any community. Although not explored in 789 the current study, it is suspected that such concern may 790 likely contribute to non-compliance of treatment. Future 791 792 research should also explore this aspect to further consolidate our understanding in the effort to provide a more 793 794 comprehensive approach to addressing Indigenous mental health. 795

796 Nevertheless, despite its preliminary and limited nature, 797 the findings in the current study were able to capture some pertinent issues relating to assessment and treatment of 798 ADHD in this Australian Aboriginal community, particu-799 larly regarding cultural appropriateness of mental health 800 programmes. The authors of this study hope that such find-801 802 ings will give health policy makers a better informed posi-803 tion from which to make decisions concerning the allocation of resources to assist Aboriginal people to appropriately 804 805 manage ADHD. Findings arising from this study can also inform future research direction, particularly in areas of de-806 807 signing culturally appropriate mental health programs. In understanding ADHD symptomatology from a cultural per-
spective, this approach can assist healthcare professionals in
identifying appropriate interventions, which will hopefully
engage and retain Aboriginal people in treatment.808
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