

Chronic Health and Lifestyle Problems for People Diagnosed with Autism in a Student-led Clinic

Research paper

Abstract

Purpose

People with Autism Spectrum Disorder (ASD) are at greater risk of developing chronic health and risky lifestyle problems. This is exaggerated further for people living in rural settings and from cultural backgrounds traditionally underserved by healthcare services. This paper describes an evaluation of health and behavioural lifestyle outcomes of people diagnosed with ASD in a student-led clinic in rural/regional Australia.

Design/methodology/approach

Routine clinical outcomes and lifestyle measures were routinely collected at a primary care student-led Clinic in rural/regional Australia. Participants were all attending the clinic who provided consent for their routine data to be reported. Participants ranged in age from new born to one hundred years and were representative of the local community.

Findings

The results indicate there is an increased risk for people with ASD developing chronic conditions compared to those without a diagnosis. This also resulted in higher BMI and blood sugar levels linked to diabetes and hypertension. Mental Health problems were common in people diagnosed with ASD especially anxiety disorders. Smoking was problematic for people with ASD but mainly in non-Aboriginal and Torres Strait Islanders. Alcohol use was not an increase risk in ASD.

Originality/value

Little is reported on the health and lifestyle experiences of people with ASD in rural/regional settings especially from Aboriginal and Torres Strait Islander communities. This paper gives an initial insight to the presentation of chronic conditions and harmful lifestyle choices. Possible insights into adapting or modifying care for people with ASD in rural/regional Australia is given

Key words: Autism Spectrum Disorder; Chronic Conditions; Lifestyle Choices; Aboriginal & Torres Strait Islander; Rural; Healthcare

Chronic health and Lifestyle Problems for People Diagnosed with Autism in a Student-led Clinic

Purpose

There are complex structural and social determinant of health issues affecting people living in regional and rural communities in Australia. Residents have lower life expectancy and increased risks of chronic disease. The health disparities of vulnerable groups in rural and regional Australia are pronounced especially among the Indigenous nations (Marmot, 2011, McDonald et al., 2013). People with mental health problems including diagnoses of Autism Spectrum Disorder (ASD) experience greater health disparities when living in rural and remote settings (Kelly et al., 2011) further heightened in Indigenous peoples with mental health problems (Sayers et al., 2017). In addition to specific health inequities, regional and rural Australians experience problems of poor housing, limited educational opportunities and higher rates of unemployment or frequent low paid work (National Rural Health Alliance, 2013).

The 2012 prevalence of Autism Spectrum Disorder (ASD) in Australia was 0.5% or >115 000 people. This is an increase of over 60 000 from the 2009 prevalence figure (Australian Bureau of Statistics, 2014). There are no formal mechanisms by which general practitioners (GP) can diagnose Autism in primary care in Australia which leads to inconsistencies in caring for people with such a diagnosis (Australian Medical Association, 2016). Formal diagnoses of Autism in Australia varies by state. In New South Wales, paediatricians, psychiatrists or a multi-disciplinary team provide ASD diagnoses. Once diagnosed with Autism the person can receive care through a GP Mental Health Treatment Plan (Australian Government Department of Health & Aging, 2011).

It is purported that people with Autism experience increased rates of co-morbid chronic conditions including mental health problems (Croen et al., 2015, Hinckson et al., 2013, Tyler et al., 2011). Simonoff et al. (2008) found 84% of people with ASD had a co-morbid mental health problem especially anxiety disorders and other developmental issues.

This is supported in a retrospective case review of 474 adults diagnosed with Autism which found a significant risk of anxiety disorders and obsessive-compulsive disorder (Russell et al., 2016). People diagnosed with ASD also experience co-morbid health problems including diabetes (Chen et al., 2016), cardiac, hypertension (Heffernan et al., 2017), and respiratory diseases (Axmon et al., 2017). In most cases the co-morbid conditions are those associated with social issues including lower physical activity and obesity.

There is a disparity between people with Autism receiving adequate help in rural areas compared to urban settings and indigenous peoples receive further inconsistent care (Farmer and Reupert, 2013, Murphy and Ruble, 2012). In addition, people with ASD often report unhealthy or risky behaviours including inactivity, over-eating and anti-social contact with others (Hill et al., 2014, Jones et al., 2017, McCoy et al., 2016). Alcohol and tobacco use varies in ASD. It is reported people with ASD experience lower rates of smoking and drinking of alcohol (Mangerud et al., 2014). However, in an Australian twin study those with ASD traits had an elevated risk of both smoking and drinking (Sizoo et al., 2010). The inability to access public awareness or community support programmes are reasons for poor integration of people with Autism into local life especially when living in regional and rural settings where there are limited choices for the whole population.

This primary aim of this study was to examine whether people with Autism experience higher rates of chronic health problems. A secondary aim was to determine if people with a diagnosis of Autism experience greater lifestyle problems including obesity and increased risk of drinking and smoking. Finally, the study aimed to determine if there were specific demographic differences in both chronic health presentations and harmful behavioural choices.

Methods

Setting and services

All subjects attended a student-led primary care clinic (SLC) based in a local community health centre. This clinic addressed the shortage of health professional student places in regional and rural Australia, especially nursing (Stuhlmiller and Tolchard, 2015,

Stuhlmiller and Tolchard, 2017). Clinic attendee data was entered into a patient management database—Best Practice, which provides output, outcomes and financial reporting (www.bpssoftware.net). A local Aboriginal Health Service managed the service.

Clinic participants

Clinic attendees considered at risk of ASD received a diagnosis prior to receiving care in the SLC. A GP, Nurse Practitioner or mental health specialist supported student-led treatments. Management of all attendees with a diagnosis of ASD was through their GP Mental Health Treatment Plan. Distinctions are made between gender and age as well as if someone identifies as Aboriginal or Torres Strait Islander. The percentage of people identifying as Aboriginal was high compared to the surrounding region. No other ethnic distinctions were made as those not identifying as indigenous were white Australians.

Table 1 gives the demographic profile of the clinic compared with the local community. There were no significant differences between demographic profile and whether someone was diagnosed with Autism. Compared to the wider community, clinic attendees were more likely to be Aboriginal or Torres Strait Islander, female and young (Table 1).

Insert Table 1 here

Of one 1564 clinic attendees assessed 3.84% or 60 people were diagnosed with Autism. This figure is from a sub-sample at risk of ASD therefore, the actual percentage in the clinic is likely much lower. The demographic profile of people with Autism, not surprisingly, were younger ($\chi^2(1, 564) = 327.49, p < .001$) and male ($\chi^2(1, 564) = 36.10, p < .001$). There were no differences on whether someone identified as Aboriginal or Torres Strait Islander.

Statistical analysis

Comparisons were made between those with and without ASD. Continuous variables were treated as dependent with ANOVA statistics being performed to determine differences. All categorical and nominal data were reported using either descriptive or non-parametric

statistics. Risk of chronic disease with ASD was established using odds ratios with lower and upper limits.

Findings

Health problems

Overall, people diagnosed with ASD were at greater risk of co-morbid health and mental health problems compared with those without a diagnosis (Table 2). The increased risks were 4.52 times higher for mental health, 4.37 times higher for cardiac problems, 3.34 times higher for diabetes and 6.27 times higher for hypertension. There was no increased risk for renal or respiratory problems. When examining the nature of the mental health problem, all diagnosed with ASD had an anxiety disorder and were over 18 years old.

Insert Table 2 here

Lifestyle problems

Obesity

Body mass index (BMI) was recorded on two occasions—assessment, then at 12-week follow-up. When comparing BMI at risk groups, people diagnosed with ASD were at greater risk of being overweight or obese (ASD: Odds ratio = 1.44 [0.73 – 2.86]). Therefore, people with ASD were 1.44 times more likely to be overweight or obese. All clinic attendees with a BMI recording showed reductions in their scores (Table 3). A one-way Analysis of Variance of the BMI mean difference revealed no significant difference between changes in BMI for those with or without ASD. However, those without ASD had a larger mean difference. In both groups, there was a shift from obese to overweight.

Insert Table 3 here

Blood sugar levels

A one-way multivariate analysis of variance (one way MANOVA) was run to determine the effect of a diagnosis of ASD and blood sugar levels. Two measures of blood sugar were assessed: Blood Sugar Level (BSL) and Fasting Blood Glucose (FBG). There was homogeneity of variance-covariance's matrices, as assessed by Box's test of equality of covariance matrices ($p = .085$) and there was homogeneity of variances, as assessed by Levene's Test of Homogeneity of Variance ($p > .05$), therefore the one-way MANOVA was able to be carried out. Clinic attendees diagnosed with ASD scored higher in their BSL ($M = 7.56, SD = 3.2$ and $M = 6.89, SD = 3.8$) and FBG ($M = 6.34, SD = 3.0$ and $M = 6.14, SD = 4.1$) compared to those without a diagnosis. There was no statistically significant difference between a diagnosis of ASD or no ASD on the combined dependent variables, $F(2, 784) = 0.536, p = .585$; Pillai's Trace = .001; partial $\eta^2 = .001$.

Tobacco and alcohol use

There was no difference between having a diagnosis of ASD and alcohol use. There was an increased risk for smoking in people with ASD compared to those without a diagnosis (OR = 2.82, 1.70-4.69; *Fishers exact p = 0.04*). People with ASD were 2.9 times more likely to be smokers (Table 4).

Insert Table 4 here

Discussion

In summary, people diagnosed with ASD are at increased risk of chronic health problems and the effects of harmful lifestyle choices. Overall, the increased risks ranged between 3.34 and 6.27 times higher than people without ASD. People with ASD were 1.44 times more likely to be overweight or obese. Overall, people with and without ASD showed improvements in their BMI levels while attending the clinic. While there were no differences between someone diagnosed with ASD or not and drinking, people with ASD were 2.9 times at greater risk of being a smoker.

The risk of experiencing co-morbid health and mental health problems in people diagnosed with ASD is higher than those without a diagnosis. In this sample all diagnosed as such were experiencing anxiety problems. In terms of mental health, having an anxiety disorder is reported in a number of studies and so these findings confirm this (Reaven, et al., 2016; Vasa, et al., 2016).

It was also found in this sample that all of those with a co-morbid diagnosis experienced higher BMI and blood sugar levels. In all cases those with ASD fell within the overweight or obese risk areas. This again has been reported in a small number of studies where being overweight or obese are at least as high as other children and adolescents and in many cases higher (Curtin, Jojic and Bandini, 2014; McCoy, Jakicic and Gibbs, 2016). The raised blood sugar levels and a greater risk of diabetes in people with ASD are likely linked. Therefore, identifying those at risk from this group and targeting the health prevention strategies may require modified or specific approaches. One example, in this study population was to provide 24-hour blood sugar monitoring with lifestyle diaries. This approach helped people understand changes in their blood sugar levels related to their lifestyle choices such as alcohol use, eating and exercise. A future strategy of the SLC could be to provide this monitoring for people with ASD and offer individual or group feedback to try and encourage lifestyle changes.

The clinic offered a number of services to try and alleviate chronic health problems through early intervention including a walking club, after school healthy eating, social club, yoga and smoking cessation classes. These programmes are designed to engage the local community in healthier lifestyle and disease management strategies. Such approaches are known to be effective in people with intellectual disabilities and ASD (Roll, 2017). The various healthy eating and exercise programmes of the clinic appear to have had a positive effect overall on levels of obesity as measured by BMI. While clinic attendees diagnosed with and without ASD showed improved BMI scores over the twelve-week period of measurement, those with ASD had a lower BMI change score. Therefore, working with those identified with ASD on better nutrition and exercise on specific goals may prove beneficial.

While the evidence is limited, there are studies examining the benefits of such interventions (Ferreira et al, 2018; Srinivasan, Pescatello and Bhat, 2014).

While the SLC provides smoking cessation opportunities, it appears those with ASD continue to smoke. The SLC professionals may need to consider how the cessation messages are being given to this group and modify them accordingly. Little is known about smoking cessation programmes for people with ASD. However, examples of specific programmes have been reported (Tracy and Hosken, 1997).

An unexpected finding was that people identifying as Aboriginal or Torres Strait Islander with a diagnosis of ASD did not appear to be at greater risk than those not identifying as such. Those without a diagnosis of ASD and having smoking and drinking problems were from the Aboriginal and Torres Strait Islander group. This community was nearly 75% Aboriginal and even allowing for weighting of cultural background these differences remained the same. It would be valuable to examine any cultural differences in how Aboriginal clinic attendees with ASD are somehow protected from these lifestyle choices. Perhaps they are receiving more services that help them in this area, or the Aboriginal community which is traditionally close knit may ensure they are not encouraged to smoke and drink. Further investigation will be needed to tease out these issues.

Overall, the risks and protective factors described in this population may reflect the wider health and lifestyle disparities associated with rural and regional settings and social deprivation especially poverty. The area from which the SLC served was considered to be one of the most deprived in Australia (ABS, 2011). Therefore, inflated risk of chronic disease, obesity and smoking may simply reflect the reality of such a community, whom they are largely underserved and experience multiple deprivations such as high crime, poor housing and limited education. In addition, a community predominantly identifying as Aboriginal and Torres Strait Islander face even greater burdens including vastly reduced life expectancy and ill health. There was a sense of ownership by this part of the community of the SLC and a desire for the clinic to work. This may have been reflected in the people diagnosed with ASD being on certain measures no worse than those without a diagnosis and in some

situations being better such as with alcohol use. Parents from Aboriginal and Torres Strait Island backgrounds often volunteered in the clinic activities including offering a soup kitchen in the evenings, providing fresh fruit to children after school and a mother and baby support group, all of which directly addressed the concerns of the community. It is believed this direct community engagement alongside the SLC activities was responsible for reduced petty crime and improved school attendance, through a greater civic pride.

References

- AUSTRALIAN BUREAU OF STATISTICS [ABS] 2014. Prevalence of Autism. Canberra, Australia: ABS.
- AUSTRALIAN BUREAU OF STATISTICS [ABS] 2011. Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia, 2011. Canberra, Australia: ABS.
- AUSTRALIAN GOVERNMENT DEPARTMENT OF HEALTH & AGING 2011. GP Mental Health Treatment Plan. Canberra, Australia: Author.
- AUSTRALIAN MEDICAL ASSOCIATION 2016. Autism Spectrum Disorder. AMA Position Statement. VCanberra, Australia: AMA.
- AXMON, A., AHLSTRÖM, G. & HÖGLUND, P. 2017. Prevalence and treatment of diabetes mellitus and hypertension among older adults with intellectual disability in comparison with the general population. *BMC geriatrics*, 17, 272.
- CHEN, M.-H., LAN, W.-H., HSU, J.-W., HUANG, K.-L., SU, T.-P., LI, C.-T., LIN, W.-C., TSAI, C.-F., TSAI, S.-J. & LEE, Y.-C. 2016. Risk of developing type 2 diabetes in adolescents and young adults with autism spectrum disorder: a nationwide longitudinal study. *Diabetes care*, 39, 788-793.
- CROEN, L. A., ZERBO, O., QIAN, Y., MASSOLO, M. L., RICH, S., SIDNEY, S. & KRIPKE, C. 2015. The health status of adults on the autism spectrum. *Autism*, 19, 814-823.
- CURTIN, C., JOJIC, M. and BANDINI, L.G., 2014. Obesity in children with autism spectrum disorders. *Harvard review of psychiatry*, 22(2), p.93.
- FARMER, J. & REUPERT, A. 2013. Understanding autism and understanding my child with autism: An evaluation of a group parent education program in rural Australia. *Australian Journal of Rural Health*, 21, 20-27.
- FERREIRA, J.P., TOSCANO, C.V.A.T., RODRIGUES, A.M., FURTADO, G.E., BARROS, M.G., WANDERLEY, R.S. and CARVALHO, H.M., 2018. Effects of a physical exercise program (PEP-Aut) on children's with autism stereotyped behaviour metabolic and physical activity profiles, physical fitness and health related quality of life: Study protocol. *Frontiers in Public Health*, 6, p.47.
- HEFFERNAN, K. S., COLUMNA, L., RUSSO, N., MYERS, B. A., ASHBY, C. E., NORRIS, M. L. & BARREIRA, T. V. 2017. Brief Report: Physical Activity, Body Mass Index and Arterial Stiffness in Children with Autism Spectrum Disorder: Preliminary Findings. *Journal of autism and developmental disorders*, 1-7.
- HILL, A. P., ZUCKERMAN, K. E., HAGEN, A. D., KRIZ, D. J., DUVALL, S. W., VAN SANTEN, J., NIGG, J., FAIR, D. & FOMBONNE, E. 2014. Aggressive behavior problems in children with autism spectrum disorders: prevalence and correlates in a large clinical sample. *Research in autism spectrum disorders*, 8, 1121-1133.
- HINCKSON, E. A., DICKINSON, A., WATER, T., SANDS, M. & PENMAN, L. 2013. Physical activity, dietary habits and overall health in overweight and obese children and youth with intellectual disability or autism. *Research in developmental disabilities*, 34, 1170-1178.

- JONES, R. A., DOWNING, K., RINEHART, N. J., BARNETT, L. M., MAY, T., MCGILLIVRAY, J. A., PAPADOPOULOS, N. V., SKOUTERIS, H., TIMPERIO, A. & HINKLEY, T. 2017. Physical activity, sedentary behavior and their correlates in children with Autism Spectrum Disorder: A systematic review. *PloS one*, 12, e0172482.
- KELLY, B. J., LEWIN, T. J., STAIN, H. J., COLEMAN, C., FITZGERALD, M., PERKINS, D., CARR, V. J., FRAGAR, L., FULLER, J. & LYLE, D. 2011. Determinants of mental health and well-being within rural and remote communities. *Social psychiatry and psychiatric epidemiology*, 46, 1331-1342.
- MANGERUD, W. L., BJERKESET, O., HOLMEN, T. L., LYDERSEN, S. & INDREDAVIK, M. S. 2014. Smoking, alcohol consumption, and drug use among adolescents with psychiatric disorders compared with a population based sample. *Journal of adolescence*, 37, 1189-1199.
- MARMOT, M. 2011. Social determinants and the health of Indigenous Australians. *Med J Aust*, 194, 512-3.
- MCCOY, S. M., JAKICIC, J. M. & GIBBS, B. B. 2016. Comparison of obesity, physical activity, and sedentary behaviors between adolescents with autism spectrum disorders and without. *Journal of autism and developmental disorders*, 46, 2317-2326.
- MCDONALD, E. L., BAILIE, R. & MICHEL, T. 2013. Development and trialling of a tool to support a systems approach to improve social determinants of health in rural and remote Australian communities: the healthy community assessment tool. *International journal for equity in health*, 12, 15.
- MURPHY, M. A. & RUBLE, L. A. 2012. A comparative study of rurality and urbanicity on access to and satisfaction with services for children with autism spectrum disorders. *Rural Special Education Quarterly*, 31, 3-11.
- NATIONAL RURAL HEALTH ALLIANCE 2013. A snapshot of poverty in rural and regional Australia. Canberra, Australia: Author.
- REAVEN, J., ACOSTA, S. and BUTCHER, C., 2016. Identifying and Addressing Anxiety in Children with Autism Spectrum Disorder. *Center for Development and Disability*.
- ROLL, A. E. 2017. Health promotion for people with intellectual disabilities—A concept analysis. *Scandinavian Journal of Caring Sciences*.
- RUSSELL, A. J., MURPHY, C. M., WILSON, E., GILLAN, N., BROWN, C., ROBERTSON, D. M., CRAIG, M. C., DEELEY, Q., ZINKSTOK, J. & JOHNSTON, K. 2016. The mental health of individuals referred for assessment of autism spectrum disorder in adulthood: a clinic report. *Autism*, 20, 623-627.
- SAYERS, J. M., CLEARY, M., HUNT, G. E. & BURMEISTER, O. K. 2017. Service and infrastructure needs to support recovery programmes for Indigenous community mental health consumers. *International journal of mental health nursing*, 26, 142-150.
- SIMONOFF, E., PICKLES, A., CHARMAN, T., CHANDLER, S., LOUCAS, T. & BAIRD, G. 2008. Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47, 921-929.
- SIZOO, B., VAN DEN BRINK, W., KOETER, M., VAN EENIGE, M. G., VAN WIJNGAARDEN-CREMERS, P. & VAN DER GAAG, R. J. 2010. Treatment seeking adults with autism or ADHD and co-morbid substance use disorder: prevalence, risk factors and functional disability. *Drug and Alcohol Dependence*, 107, 44-50.
- SRINIVASAN, S. M., PESCATELLO, L. S., & BHAT, A. N. (2014). Current perspectives on physical activity and exercise recommendations for children and adolescents with autism spectrum disorders. *Physical therapy*, 94(6), 875-889.
- STUHMILLER, C. M. & TOLCHARD, B. 2015. Developing a student-led health and wellbeing clinic in an underserved community: collaborative learning, health outcomes and cost savings. *BMC nursing*, 14, 32.

- STUHMILLER, C. M. & TOLCHARD, B. 2017. Population Health Outcomes of a Student-Led Free Health Clinic for an Underserved Population: A Naturalistic Study. *Journal of community health*, 1-8.
- TRACY, J. & HOSKEN, R. 1997. The importance of smoking education and preventative health strategies for people with intellectual disability. *Journal of Intellectual Disability Research*, 41, 416-421.
- TYLER, C. V., SCHRAMM, S. C., KARAFKA, M., TANG, A. S. & JAIN, A. K. 2011. Chronic disease risks in young adults with autism spectrum disorder: forewarned is forearmed. *American journal on intellectual and developmental disabilities*, 116, 371-380.
- VASA, R.A., CARROLL, L.M., NOZOLILLO, A.A., MAHAJAN, R., MAZUREK, M.O., BENNETT, A.E., WINK, L.K. and BERNAL, M.P., 2014. A systematic review of treatments for anxiety in youth with autism spectrum disorders. *Journal of autism and developmental disorders*, 44(12), pp.3215-3229.