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Title: "The single most important thing that has happened to me in my life": Development of the Impact of Diagnosis Scale – Preliminary Revision (IODS-PR)

Keywords

Autism, Diagnosis, Assessment

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Abstract

Background: Awareness and diagnosis of autism in adulthood is on the rise. Studies have considered the impact of receiving an autism diagnosis for parents of children on the spectrum, though only few primarily qualitative studies have considered the self-reported impact of autism diagnosis. The Impact of Diagnosis Scale (IODS) was initially developed with a focus on borderline personality disorder. Our aim was to develop a version suitable for autistic individuals.

Method: The research team and a group of autistic advisors revised the IODS items for suitability and accessibility to autistic participants. We gathered participant data for ninety-two autistic adolescents and adults from the Cooperative Research Centre for Living with Autism (Autism CRC) Study of Australian School Leavers with Autism (SASLA) and the Australian Longitudinal Study of Autism in Adulthood (ALSAA). We used iterated principal factors analysis to explore potential factors, and thematic analysis to explore responses to two open-ended items.

Results: Factor analysis suggested three factors of "Service Access", "Being Understood" and "Self-Acceptance and Understanding" for the 12 items of the IODS-Preliminary Revision (IODS-PR). Cronbach's α was good overall and acceptable for subdomains. Item mean scores suggest although impact of autism diagnosis was generally perceived as positive for Self-Acceptance and Understanding, scores were neutral in other domains. Qualitative analysis identified themes of *Self-Understanding, Identity and Acceptance, Support and Services, Valence of Response, Relationships* and *Camouflaging*.

Conclusions: The IODS-PR is the first scale to measure the self-reported experience of receiving an autism diagnosis. It showed good psychometrics and provides new insight into the experience of autism diagnosis. Qualitative analysis identified domains that remain unexplored and the potential for an expanded item set. A further revision of the tool will soon be available. It will provide critical information for clinicians and has potential applications for research and service evaluation.

Introduction

Rising public awareness, diagnoses in females[1] and cases of less pronounced autistic traits[2] are factors contributing to an overall increase in autism spectrum diagnoses in adulthood. Researchers referred to individuals receiving a late autism diagnosis as a "lost generation",[3] as they have spent a large proportion of their life without the benefit of early identification and supports. To date, limited qualitative work in this area describes that receiving a diagnosis in adulthood can be a life changing "emotional roller coaster"[4] that elicits feelings of relief and provides a framework for understanding and sense of belonging.[4–8] However, more research is needed to understand, support, and accommodate the increasing number of individuals receiving a late autism diagnosis.

Evidence from both survey[4,6,8] and interview-based[5,9] methods suggest a generally positive impact of receiving an autism spectrum diagnosis in adulthood. Adults from qualitative studies described feelings of being different and experiences of unexplained social and occupational difficulties prior to diagnosis.[4,5,9] Participants reported feelings of relief after diagnosis,[6,8] as this new understanding allowed them to re-interpret their experiences in a manner that promotes self-acceptance.[4,5,9] Adults described that increased self-understanding helped them develop more effective coping strategies for everyday situations.[4] However, some adults also experience sadness and anger after diagnosis,[6] most commonly because they wish they had been diagnosed earlier or due to uncertainty over availability of support.[8] Despite the lack of formal support services,[6] evidence illustrates that receiving a diagnosis enables autistic adults to access peer-led autistic communities in-person and online, which can provide a sense of belonging and acceptance.[4,5,9]

Despite the reports regarding the impact of adult diagnosis, there is currently no empirically supported psychometric tool measuring the impact of receiving an autism

diagnosis in adulthood. Impact of diagnosis research has focused on the mostly negative emotional response of parents whose child is diagnosed on the spectrum,[10] or been framed as a negative and stressful event in cancer and diabetes diagnosis,[11,12] but little if any research has been conducted with other conditions. Courtney and Makinen[13] originally developed the 10-item Impact of Diagnosis Scale (IODS) to explore the impact of receiving a borderline personality disorder diagnosis in adolescents. They gathered preliminary data one-month post-diagnosis from 25 Canadian adolescents who had attended an inpatient unit. The 21 useable responses showed a modest internal consistency for the IODS (Cronbach α = .66), with a spread of responses to the items; in general participants felt their diagnosis was accurate and helped them understand their symptoms. The scale authors identified the need for further development of the IODS, suggested revision of items relating to psychological validation, adding new items relating to hope and shame, and co-production in the tool's design.

Given the lack of suitable measures to investigate self-reported impact of diagnosis, the aim of the current study was to validate a revised version of the IODS designed to explore the impact of receiving an autism spectrum diagnosis in older autistic adolescents and adults. A secondary aim was to gather data to guide potential future revisions of the tool. Our autistic research participants and advisors highlighted exploration of autism diagnosis in adulthood as a topic of enquiry.[14] It is intended that the measurement of the impact of diagnosis may potentially be used to influence clinical practice, as without understanding the impact of diagnosis it is not possible to provide evidence-based support to autistic adults during this experience.

Method

Participants and Procedures

We gathered participant data for this study from the Study of Australian School Leavers with Autism (SASLA)[15] and the Australian Longitudinal Study of Autism in Adulthood (ALSAA; formerly known as the Australian Longitudinal Study of Adults with Autism).[14] Both studies are questionnaire-based, prospective, longitudinal cohort studies of autistic school leavers (15-25 years) and autistic adults (25+ years) respectively and have ethics approval from the relevant institutions. The SASLA and ALSAA studies recuited participants through advertisement and contact with autism, disability or education-related organisations. Participants completed online or hardcopy surveys with a large battery of measures containing the revised version of the IODS. Participants self-reported their autism diagnosis, as well as providing details of diagnosing clinicians and completed the Autism Spectrum Quotient-28.[16] Full details of the SASLA and ALSAA samples and procedures are described elsewhere.[14,15]

From an available 169 respondents, a total of 92 autistic participants provided usable quantitative data (46 males, 38 females, 8 non-binary; $M_{age} = 35.62$ years, $SD = 15.62$, range 15–71 years). For these participants, the average age of receiving a diagnosis was 29.59 years ($SD = 17.32$, range 2-63, $n=5$ missing) and average years since receiving diagnosis was 7.25 ($SD=6.98$, range 0 to 40, $n=5$ missing). Participants' year of diagnosis ranged between 1977-2018. Many had co-occurring mental health conditions (depression $n=48$, 52%; anxiety $n=59$, 64%), and some were studying ($n=35$, 38%, $n=1$ missing) or were employed ($n=41$, 46%, $n=2$ missing). We included all $N=169$ participants in qualitative analysis.

Instrument

The Impact of Diagnosis Scale - Preliminary Revision (IODS-PR) was developed with input from the ALSAA Research Advisory Network (RAN) of autistic advisors. Three autistic advisors reviewed the scale, prior to data gathering, with a focus on wording of modified

items developed by the research team (SA & LL). The IODS-PR consisted of 12 items (see Appendix 1) each scored on a 7-point Likert scale (Strongly Disagree – Strongly Agree), with a Not Applicable (NA) option. Four items (3, 5, 6, 10) were reverse scored. Higher scores indicated a more positive impact of diagnosis. In comparison to the original IODS, we split two items, with "access treatment" separated into "access to community supports" and "access to healthcare supports", and "diagnosis made me feel better" separated into "feel better physically" and "feel better about myself". We removed words such as "symptoms", as autism was conceptualised as a condition, not a disorder, hence the word "symptom" would be inaccurate. We also revised instructions to ask participants the exact autism spectrum diagnosis they received, given that many would have been diagnosed under DSM-IV or DSM-IV-TR,[17] and to write this into spaces provided within several items, which is automated when completing the online survey. There were two additional qualitative items, asking for (1) reasons why any items were scored NA, and (2) any further comments on impact of receiving diagnosis. We used the first item "I clearly remember a clinician using the diagnostic term ……………. to describe some of my life experiences" as a screening item, where we considered participants who disagreed with this item unlikely to be able to complete a valid questionnaire. Although the original IODS used the first two items for screening, we included the second item "I have learned about …………………………. and the indications of the condition" in domain scoring.

Inclusive Research Process

The ALSAA study recruited RAN advisors through established networks of the researchers, the Autism CRC Research Academy, and later open calls to ALSAA participants. For this study, we sent autistic advisors emails with attached lay summaries,

instructions and timeframes for providing input, and draft versions of the tool, inviting them to provide input to the scale development. Three advisors who had already established their preferred methods of communication responded. Their feedback was received through various formats, including written responses via email or letter, and video conferencing. Advisors provided feedback on visual formatting, clarity of instructions for participants, and added clarity to assessment items. We then sent advisors a summary outlining which aspects of their advice had been incorporated, or were unable to be incorporated into the IODS-PR. One advisor reviewed the qualitative findings within this manuscript.

Data Analysis

We used STATA 15[18] for all quantitative analysis, including descriptive statistics, psychometrics and factor analysis.

We used QSR International's NVivo 12[19] for qualitative thematic analysis. For the thematic analysis, we practiced an inductive approach to coding, attempting to derive themes from the data itself and avoid theoretical bias. The first rater (SA) completed inductive coding across all responses to generate possible themes. In discussion with the second rater (JH), we grouped and collapsed theme where possible. Themes with <2 coded entries collapsed into 'uncategorised'. The second rater then completed independent coding of 1/3 of the responses to the agreed themes to determine inter-rater reliability.

Results

Quantitative Analyses

We excluded numerous participants (n=77) due to incomplete or NA responses on some items (n=67) as it was not possible to calculate a total score, e.g., scoring not applicable on items '…getting access to community supports…' (n=35) and / or '…access to healthcare supports…' (n=23), and/or due to not remembering being diagnosed based on the screening item (n=15). Excluded participants were older (t(167)=-1.80, p=.03), but we found no significant differences in gender (n=15 missing), age of diagnosis, or years since diagnosis between included and excluded participants. The original IODS did not include an NA option, but we thought it was important to include for scale development purposes to ensure items were relevant to receiving an autism diagnosis. For the remaining n=92 participants, the Kaiser-Meyer-Olkin (KMO) test (KMO=0.70) and Bartlett's test of sphericity (X^2(55) = 353.28, p<0.001) both indicated the data were acceptable for factor analysis. Following review of eigenvalues, scree plots, and the optimal combination of Akaike's and Bayesian Information Criterion values (AIC=184, BIC=190 for the three-factor model), we conducted a three-factor exploratory factor analysis using the iterated principal factors method[20] with Promax rotation. We identified three factors based on factor loadings: *Self-Acceptance and Understanding* (SU), *Being Understood* (BU) and *Service Access* (SA) (see Table 1). SU encompassed a new positive understanding of past life experiences, BU referred to others treating the person with more understanding following diagnosis, and SA referred to access to community and healthcare supports following diagnosis. Cronbach's alpha and average inter-item correlations suggest the 11 scored items overall (α=0.69, r=0.18) and the factor SU (α=0.78, r=0.35) show good internal consistency, but factors BU (α=0.81, r=0.68) and SA (α=0.73, r=0.58) would benefit from greater variety in items.

Descriptive statistics (Table 2) showed the impact of diagnosis was generally positive for SU, though relatively neutral for BU and SA. Items from SU received neutral-to-high scores with negative skew, indicating positive impact in this domain. In contrast, BU and SA

items received low to neutral scores. Pearson correlations showed weak non-significant relationships between factors (r = -.06 to .18).

Thematic Analysis

Of 160 meaningful responses to the two open-ended items, 12 responses remained uncategorized. The second rater had >95% agreement with coding 1/3 of the responses. We identified five overarching themes: '*Self Understanding, Identity and Acceptance', 'Support and Services', 'Valence of Response', 'Relationships'* and *'Camouflaging'*.

The strongest theme to emerge related to *Self-Understanding, Identity and Acceptance*. Participants commented that the diagnosis was beneficial in helping them understand themselves. One participant remarked with an improved sense of identity and self-acceptance that "It allowed me to see myself as a perfectly normal, average, Autistic person instead of a weird, failed, flawed non-Autistic person. It has completely changed the way that I perceive and describe myself" with another stating autism diagnosis was "The single most important thing that has happened to me in my life". However, a positive self-understanding was sometimes hindered by social stigma: "Because autism is still classified as a 'disorder', I found that aspect very difficult to integrate into my life and sense of self without feeling down about myself and the world."

The *Supports and Services* theme contains subcategories *Enabled Support, Support not needed* and *No or poor services*. Although some received "a lot more help and support since I was diagnosed", it appears for many, as supported by the quantitative data, that "the downside of the diagnosis was that there was no follow-up by way of ongoing support and there never has been." Further supported by the number of NA responses to the related quantitative items, some participants commented that "I do not need or want support", though comments in this category were sometimes related to the lack of appropriate services: "I have

never applied for community supports. (Although, the more I look, the more I see that there are next to none to apply for in any case.)"

The *Valence of Response* theme contains subcategories *Relief, Positive impact, Wish diagnosed earlier* and *Negative impact*. A common response was "overwhelming relief of knowing I was born this way and that there is nothing wrong with me." In alignment with quantitative data many gave positive comments: "Other than having my children, my diagnosis is the best thing that ever happened to me", though not all responses were positive, with some expressing regret they were not diagnosed earlier: "I still feel a lot of grief about things (mistakes due to miscommunication/misunderstanding the situation, abuse, etc) that I feel could have gone differently if I had had an earlier diagnosis." There were also some negative responses, with a participant becoming reclusive, another losing their career, and one commenting: "Since diagnoses (sic) advising peers and colleagues gives me a sense of dread and fear of being victimised and excluded."

The *Relationships* theme contains subcategories *Connected with autistic community, Improves relationships* and *Others lack understanding*. Some participants commented on a key benefit of diagnosis that "Maybe most importantly, getting my diagnosis prompted me to seek out the Autistic community, and … connections and friendships within my Autistic tribe". Participants also mentioned improvements to relationships: "Helped me understand previous relationship difficulties and also helps my wife and I with our current relationship." Though some also mentioned negative aspect of relationships relating to a lack of understanding of autism: "I haven't felt that I have received extra understanding from professionals, in fact I have felt it has worked against me in some situations, especially medical situations where Autism seems to equate to 'anxiety' in some people's minds".

The final theme identified related to *Camouflaging*, with comments like "I discovered that I was 'faking' my way through most of life, so since my diagnosis I have been going through a lot of self-exploration and working out who 'I' really am, rather than who I might be pretending to be."

Discussion

The aim of this study was to develop a revised version of the IODS to examine the impact of receiving an autism spectrum diagnosis. Quantitative results identified three factors within the IODS-PR: Self-Acceptance and Understanding (SU), Being Understood (BU) and Service Access (SA). Scores suggested a generally positive impact to SU from receiving a diagnosis of autism, and a relatively neutral impact to BU and SA. Qualitative data highlighted that for most people, receiving an autism diagnosis is a life-changing and mostly positive experience, though more needs to be done regarding post-diagnosis support and community understanding and acceptance. Valuable information has been gained to inform further revision of the tool.

Importantly, we excluded many participants from the quantitative data analysis, primarily due to NA responses to items related to accessing supports. Many participants commented they did not need further health or community supports post-diagnosis. Traditional scale development processes might suggest these items should be removed. However, these items relate to areas of critical clinical interest. Future versions of the IODS will need to ensure a scoring system that provides meaningful results for participants who score NA on these items. The screening item "I clearly remember a clinician using the diagnostic term…" may also need revision to clearly determine if there was an event related to the disclosure or discovery of a formal diagnosis.

Our findings for autistic participants add support to existing studies[6] of autism diagnosis in adulthood, of a strong positive impact in terms of self-understanding, some improvement in well-being and relationships, though generally poor post-diagnosis support services. The generally positive impact of receiving an autism diagnosis may be diminished by the lack of post-diagnostic support. Future research could consider examining the impact of diagnosis over time and whether it is influenced by clinician practices and the adequacy of post-diagnosis support.

Analysis of qualitative data adds further context to this preliminary analysis on the impact of autism diagnosis. Of interest, although not a specific topic area we probed, the theme of camouflaging that emerged emphasises the centrality of this process in autistic social experiences as suggested by recent research.[21,22] Undiagnosed adolescents and adults may not realise their experience of camouflaging is related to their neurodivergence. It appears that although overall diagnosis may be a positive experience in terms of self-understanding, a more mixed response in terms of relationships with others is consistent with previous studies,[7,23] and likely is dependent upon the level of acceptance and understanding of the other party. A generally positive response in terms of self-understanding also needs be contextualised to the variety in valence of responses from the qualitative data, as other studies highlighted both positive and negative emotional reactions.[4,6,8] Neutral quantitative scores on BU and mixed qualitative responses in terms of relationships should be considered in terms of the difficulty in perspective-taking for some autistic participants, future studies could cross-validate with another party's perspective (e.g., spouse, sibling, parent) on perceptions and access to supports post-diagnosis. We also suspect that the perceived impact of diagnosis will change depending on time since diagnosis, which could be an important area for longitudinal studies.

A key strength of the IODS-PR is the involvement of autistic advisors in its development. Inclusive approaches may particularly benefit scale development, aligning the constructs and their mode of measurement to the understanding of those on the autism spectrum, rather than that of naïve outsider perspectives, who may assume items are easily comprehensible. Thus, using autistic advisors ensures the tool has meaning[24] and applicability to the population it is intended to measure. More rigorous engagement with autistic advisors and researchers is underway in developing a further revision of the tool.

Limitations and Future Directions

There are both strengths and limitations to using a questionnaire tool to explore the topic of impact of diagnosis. For example, the measurement of this construct will allow the identification of related factors that can inform diagnostic practices. However, we were unable to determine potential confounders such as the individual's acceptance or denial of the diagnosis, and their awareness of what supports might be available from the data gathered. Although the two qualitative items intended for scale development purposes did gather a surprising richness of data from several participants, interview or focus group research would be able to obtain a depth of understanding that may be overlooked using a purely questionnaire-based data gathering technique.

Validation of a revised IODS will be limited by the lack of existing tools measuring the construct. However, certain subdomains of a revised tool may align with related constructs (e.g. well-being) and allow assessment of convergent validity. No validity testing has been undertaken so far in the preliminary revision of the tool, and only internal consistency of factors was measured. Factor analysis was conducted using a small sample of n=92, though testing suggested the data were suitable for analysis. Future work validating revisions of the IODS using larger samples should be conducted.

An additional benefit to the re-design of the IODS-PR lies in its potential to inform service delivery for autistic individuals. Identifying factors that influence response to diagnosis may assist in further sensitizing clinicians in their approach to disclosing diagnoses, and to the adequacy of post-diagnosis supports and services. Most importantly, this preliminary data clearly indicates the need for development of post-diagnostic support for autistic individuals.

Considering RAN and participant interest in the topic, potential additional topic areas within the qualitative results, and small numbers of items in BU and SA domains, we decided to work towards a further revision to the tool to explore additional domains and items of interest (e.g. '*Well-being (i.e. a positive feeling of wellness)*', '*Diagnostic Process*', '*Accuracy of Diagnosis*' and '*Relating with Others*'). Further revision of the IODS intends to make it applicable to service provision evaluation and inform clinical practices, in addition to aiding understanding of the impact and outcomes of receiving an autism diagnosis in late adolescence or adulthood. Examining the impact of diagnosis over time may assist in evaluating the benefit of post-diagnostic pilot services.

Conclusion

Using an inclusive research approach, we developed the IODS-PR, which uniquely measures the self-reported impact of diagnosis. Initial findings confirm the generally positive impact of receiving a diagnosis of autism and the disappointing lack of post-diagnosis support. The IODS-PR had some good psychometric properties, though the small numbers of items in some domains and additional areas for consideration identified in qualitative analysis highlight the need for further revision of the tool. Interested clinicians and researchers are encouraged to contact the corresponding author to access future revisions of the tool which should soon be available.

Acknowledgements

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Table 1

Factor loadings of the 11 scored items in the IODS-PR (*n*=92)

Items	Loadings		
	SU	**BU**	**SA**
Factor 1: Self-Acceptance and Understanding			
2. I have learned about "….." and the indications of the condition.	.36	-.13	.11
3. … has made me very confused.	.43	-.16	.19
4. … seems to be an accurate way to describe a lot of my life experiences…	.77	.13	.02
7. Learning about "….." has helped me understand my life.	.74	.11	.02
8. …has made me feel better physically.	.64	.04	-.15
9. …has made me feel better about myself.	.65	.12	-.12
10. My life experiences are better described without using the term "…".	.64	-.20	.10

Factor 2: Being Understood			
11. …Clinicians seem to treat me with more understanding…	.05	.77	.05
12. My close family / friends seem to treat me with more understanding…	.13	.82	.06
Factor 3: Service Access			
5. …I have had a hard time getting access to community supports…	-.16	.03	.60
6. …I have had a hard time getting access to healthcare supports…	.02	.07	.94

SU: Self-Acceptance and Understanding; BU: Being Understood; SA: Service Access

Table 2

IODS-PR descriptive statistics for total, subscales and scored items, after reverse-scoring (*n*=92)

Item	Mean (SD)	Skew	Kurtosis
Factor 1: Self-Acceptance and Understanding	5.58 (.97)	-.32	2.31
2. I have learned about "….." and the indications of the condition.	6.25 (1.30)	-2.60	10.12
3. … has made me very confused.	5.40 (1.62)	-.92	2.90
4. … seems to be an accurate way to describe a lot of my life experiences…	5.89 (1.30)	-1.50	5.25
7. Learning about "….." has helped me understand my life.	6.23 (1.08)	-1.30	3.70
8. …has made me feel better physically.	4.90 (1.59)	-.35	2.30
9. …has made me feel better about myself.	5.07 (1.82)	-.60	2.18
10. My life experiences are better described without using the term "…".	5.30 (1.52)	-.75	2.73
Factor 2: Being Understood	4.54 (1.53)	-.55	2.63

11. …Clinicians seem to treat me with more understanding…	4.49 (1.63)	-.41	2.31
12. My close family / friends seem to treat me with more understanding…	4.59 (1.72)	-.59	2.46
Factor 3: Service Access	4.12 (1.54)	.07	2.46
5. …I have had a hard time getting access to community supports…	3.83 (1.74)	.12	2.22
6. …I have had a hard time getting access to healthcare supports…	4.41 (1.74)	-.17	2.05

Appendix 1 – Items used in the IODS-PR

1. I clearly remember a clinician using the diagnostic term "…………….…………" to describe some of my life experiences
2. I have learned about "………………………." and the indications of the condition
3. Hearing the term "…………………………" to describe my life experiences has made me very confused
4. Using the term "……………………......" seems to be an accurate way to describe a lot of my life experiences
5. I have had a hard time getting access to community supports (e.g., home help, recreation program) since my life experiences were described as being part of "……………"
6. I have had a hard time getting access to healthcare supports (e.g., psychiatrist or dentist) since my life experiences were described as being part of "…………………"
7. Learning about "………………………." has helped me understand my life experiences
8. Hearing my life experiences being described as part of "………………………" has made me feel better physically
9. Hearing my life experiences being described as part of "………………………" has made me feel better about myself
10. My life experiences are better described without using the term "………………………………"
11. Clinicians seem to treat me with more understanding since the term "………………………………." was used to describe my life experiences
12. My close family / close friends seem to treat me with more understanding since the term "………………………………" was used to describe my life experiences