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How is a sense of well-being and belonging constructed in the accounts of autistic adults?

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This small-scale exploratory study sought to develop an understanding of the meaning of well-being and social belonging as represented within the narratives of adults on the autism spectrum. Employing an interpretivist approach facilitated the investigation of potential contributory factors to these lived experiences in order to inform further research regarding both this topic, and service provision for adults on the autism spectrum. The project involved a thematic analysis of issues of the magazine Asperger United (AU). Four broad main themes were identified: meeting personal needs, living with the consequences of an 'othered' identity, connection and recognition, and relationships and advocacy. Autistic adults reported many barriers to feeling that they belonged in a number of social spaces and the detrimental effect this had on their wellbeing. Fundamental to positive narratives of wellbeing, were feelings of connection and recognition from others and positive accepting relationships, with autistic-led spaces, particularly the Autscape conference, being frequently cited as of central significance in increasing feelings of wellbeing and belonging. This study has demonstrated a need for less focus on remediation and more on limiting the social isolation of autistic people.

Keywords: Autism, well-being, belonging, thematic analysis

Introduction

Note: In accordance with other 'autistic voices' (Sinclair, 1993, Sainsbury, 2000) this article will use the descriptors of 'autistic person/people' and 'autistic spectrum'.

Ever since Durkheim's (1897) seminal work, social scientific theorists have debated the potential link between wellbeing and social belonging. Attempts to improve the wellbeing of those diagnosed with a psychiatric condition have frequently centred upon notions of the remediation of a functionally normative social agent to enable return to previously held societal roles (Parsons, 1951). Despite variations in definition, wellbeing is generally assumed to encompass subjective evaluation of physical, mental, social and spiritual life experiences (Friedli, 2009). However, there are questions that beg for closer examination: what do wellbeing and social belonging mean for someone on the autism spectrum? How are they practically achieved?

Studies using wellbeing indicators with adults on the autism spectrum often feature limited self-assessment measures (Bracher, 2014) and the extent to which standardised measures of wellbeing capture autistic experience and sensibilities is debatable (Robertson, 2010).

> "Most scales devised for use with the general population cannot be used with all population sub-sets" (International Wellbeing Group, 2006, p. 5).

Current measures of wellbeing used in the context of autism have been developed with a non-autistic population and hence cannot be assumed to adequately reflect an autistic perspective, although this area of research has recently been gaining increasing attention (Renty and Roeyers, 2006; Burgess and Gustein, 2007; Robertson, 2010, Billstedt et al., 2011). Renty and Roeyers (2006) highlighted the need for people on the autism spectrum to have access to support networks, as well as effective professional backup, following a comprehensive needs assessment. Burgess and Gustein (2007) suggested that wellbeing measures could be broken down into 'social functioning', such as quality of friendships, availability of social support networks, and 'emotional functioning', such as self-esteem and mental health. Billstedt et al. (2011) found there was a need for improvements in occupational and recreational activities accessed by people on the autism spectrum and suggested that more research was needed into the concept of an 'autism-friendly environment' including the development of wellbeing assessment tools designed to be relevant to the particular needs of people on the autism spectrum.

Robertson (2010), an American autistic researcher, critiqued deficit model assumptions about wellbeing for autistic people, and suggested an alternative perspective based on the concept of neurodiversity. Rather than seeing autistic people as 'broken' and in need of 'fixing', such a perspective would focus on diversity of need, and personal 'strengths' as well as 'challenges'. Robertson (2010) suggests that Schalock's (2000) quality of life framework is a good starting point for building a model for viewing core domains of wellbeing for autistic adults, and, highlights the need to develop a collaborative approach between professionals and autistic adults if meaningful solutions are to be found to meet the challenges that autistic people face in navigating social life.

Schalock (2000) reviewed research relating to quality of life measures over a thirty-year period and identified eight core domains, with relevant indicators: self-determination (autonomy, decision-making, self-direction), social inclusion (acceptance, status, community activity), material well-being (ownership, employment), personal development (education, personal competence), emotional well-being (spirituality, safety, freedom from stress), interpersonal relations (intimacy, friendship, support), rights (privacy, voting, access), and physical well-being (health, nutrition, recreation). Robertson (2010) describes Schalock's (2000) model as a non-normative approach compatible with a social model of disability, and accepting of diversity and individual efforts toward self-determination and self-advocacy.

Although supporting the non-normative approach of Schalock (2000) however, Robertson's (2010) own use of terms such as 'strengths' and 'challenges' could be seen as conceptually embedded in normative thinking.

Theorists such as Timimi et al. (2011) and Runswick-Cole (2014) have questioned the use of medicalised labels such as autism and also concepts such as neurodiversity, and the possible detrimental effects of a politics of identity. In contrast, research conducted by Beardon and Edmonds (2007), found that 83% of autistic adults they surveyed identified that one of their greatest challenges is a lack of understanding and recognition of their differing needs from other people. The same issue was highlighted by autistic children and young people in consultation exercises undertaken in the development of materials for the Milton and Giannadou (2012). Milton (2012; 2014) has previously theorised that such gaps in understanding arise from differing dispositional perceptions and ways of being in life, a mismatch of what is salient or of interest within any given context, the 'double empathy problem'. For Robertson (2010), when professionals look at the barriers autistic people face in social life, they rarely focus on how social attitudes and norms can create them. One of many examples Robertson (2010) gives refers to autistic people attaining and sustaining employment, where efforts are often concerned with adapting the autistic employee to fit into social contexts rather than adapting such contexts to meet the needs of the individual.

The study

Our small-scale exploratory study sought to develop an understanding of the meaning of wellbeing and social belonging as represented within the narratives of adults on the autism spectrum. Employing an interpretivist approach facilitates the investigation of potential contributory factors to these lived experiences in order to inform further research regarding both this topic, and service provision for adults on the autism spectrum.

The project involved a thematic analysis of issues of the magazine Asperger United (AU). AU was founded in 1993 and is run by and for adults on the autism spectrum, although some parents subscribe to it on behalf of their children. Since the year 2000 AU has been supported by the National Autistic Society (NAS). Themes and issues relevant to adults on the spectrum and expressed through the articles within AU were collated and analysed, with particular attention given to references made to factors that have influenced, either positively or negatively, an individual's sense of wellbeing or social belonging, as well as any links made in narratives between these two constructs. Although AU magazine is accessed by people across the autism spectrum, as the title of the magazine suggests, it is engaged with primarily by those with a good linguistic understanding. Not all contributors would identify with the term 'Asperger Syndrome' however, and so the wider terms of 'autism', 'autistic' and 'autistic spectrum' have been used as descriptors in this study.

Methods

Research Question

What is the meaning of well-being and belonging for autistic adults?

Sampling

At the time of analysis, seventy-nine editions of AU had been published. Twenty-one editions of AU were sampled from the issues available from the National Autistic Society (NAS) information service, ranging over a six-year period from issue number 54, April 2008, through to issue 78, April 2014. Issues including articles written by the researchers were excluded from the study (issues 71, 72 and 79). Issues over six years old were also excluded in order to keep the project analysis manageable and current. AU contributions are accepted in the form of articles, letters to the editor, book reviews, and pen pals. All textual information within these sections was analysed for this study, in total: 78 articles, 81 letters to the editor, 37 reviews, 121 pen pal entries, and 44 announcements were analysed.

Analysis

Thematic Analysis was selected for data analysis as, located within the interpretivist paradigm, it can be used to produce in-depth interpretative analyses, providing nuanced and complex interpretations of data (Clarke and Braun, 2013). The analytic process involved progressing from a description of the data to an interpretive account of the themes that emerged from the analysis to a discussion of their wider implications. The first author undertook first-order coding of the data, viewing the data set a number of times for familiarity before labelling basic segments of the text. The data was coded using descriptive markers, to allow as much as possible for meanings to 'emerge' from the data. Following the methodology of Braun and Clarke (2006), these first order themes were strongly linked to the data and were inductive in nature, without a predetermined frame of reference, in an attempt to limit the effects of personal preconceptions. These first order themes were then organised into meaningful groups under the second stage of the coding (Tuckett, 2005). Sub-themes were formed from this process through interpreting the data in reference to the notions of wellbeing and belonging. Finally, sub-themes were combined into meaningful clusters to develop four overarching themes. Throughout this process, the first author reflected upon possible ways that he had been affected by the process and upon his own positionality and potential bias in interpretations made. The second author then reviewed themes, subthemes and codes and further developed them to ensure internal coherence and avoid repetition between themes.

Epistemology

Influenced by the interpretive paradigm, a thematic analysis was utilised in order to capture patterns in both the lived experiences as perceived by adults on the autism spectrum, and the wider discourse that they draw upon, thus acknowledging how people make meaning from their lived experiences. The interpretivist paradigm emphasises the importance of contextualised analysis: through drawing on the wider discourse the data is interpreted and patterns identified (Gephart, 1999). However, it is recognised that interpretation of the data is infused with the concerns of the researchers.

Ethical issues

This study originated from discussions with members of the advisory committee for Research Autism and received ethical approval from the National Association of Disability Practitioners (NADP). An important ethical issue was encountered however in the decision to conduct a thematic analysis of AU magazine. Despite AU magazine being publicly available, within the autistic community there has been upset and anger expressed at how scholars in the field of autism have misinterpreted autistic community and culture, through 'quote-mining' – finding quotes to fit one's own agenda (Arnold, 2012), and 'fishbowling' – invasively inspecting and misinterpreting autistic culture from a privileged position of academic power (Moon, cited Milton and Moon, 2012). In a study of this nature, it is inevitable that the interpretation will be partial and influenced by researcher positionality. If any of the submissions to AU magazine have been misframed in this analysis, the authors apologise and hope that this does not cause upset. Readers are advised to read the writings of autistic people through public media such as the AU magazine and engage with autistic culture and the concerns of autistic people.

Results

The thematic analysis identified four main themes that encompassed a large number of sub-themes as listed in the table below:

Themes	Subthemes	Codes
Meeting personal needs	Stress reduction	- Structure - Sensory needs
	Personal fulfilment	- Interests (recreational and educational) - Spirituality and philosophy - Sexuality
Living with the consequences of an 'othered' identity	Societal othering	- Bullying - Isolation and

		alienation - Exclusion - Mental health - Normalisation - Authority - Obedience and conformity - Ableism - Stigma - Financial and employment security - Disjuncture between own and others' views of self - The double empathy problem
	Self-discovery	- Identity - Diversity - Diagnosis - Gender - Self-understanding - Personal journey
	Social navigation	- Expectations - Masking and passing - Independence and autonomy
Connection and recognition	Sharing	- Experiences - Interests
	Acceptance	- Autistic space
Relationships and advocacy	External support	- Mentoring - Advocacy
	Family and personal relationships	
	Self-advocacy	- Autistic rights - Neurodiversity

Theme 1: Meeting personal needs:

The theme of ‘meeting personal needs’ was developed from writers’ in AU’s expressions of needs relating to embodying an autistic disposition within social settings. The term ‘personal needs’ is used to emphasise the individuality of these needs and related experiences. Personal needs encompassed those relating to minimising stress and fulfilling one’s own needs and desires.

Stress reduction:

A personal need often mentioned with regard to minimising stress was that of having structure and routine in one's life. It should be said however that the structures that led to the most subjective benefit to wellbeing were structures that originated from the autistic person themselves, rather than those that were externally imposed. Another common personal need related to managing stress was the avoidance of sensory overload:

> "It makes me a very visible case of "sensory issues", when a spectrumite's body is discomforted by certain clothes and fabrics." (Maurice – 'Sensitivity and clothing', Ed. 66: 4).

On occasion however, these intrinsic needs were set within a social context with comments referring to society as being too fast paced or not accommodating a slow and deliberate style of processing or thinking, with some commenting on a preference for a rural lifestyle. The need for quiet time alone was often mentioned, yet this was set in juxtaposition with a need for connection (see theme 3).

Personal fulfilment:

A number of contributors to AU mentioned the need to express their spirituality, yet many had met with discrimination and stigma within spiritual communities. A number of contributors specifically mentioned Buddhism, or techniques such as mindfulness. Personal fulfilment was also discussed in relation to sexuality. Many contributors to AU magazine talked of being part of the LGBT (lesbian, gay, bisexual and transgender) community and the intersectional issues that were brought up for them.

The most predominant issue in relation to personal fulfilment was being able to engage in pursuits of interest. Of note was also how engagement with such activities of interest led many to report on feelings that could be described as a 'flow state' (characterised by being 'in the moment' and totally focussed on the activity at hand) (McDonnell and Milton, 2014):

> "I have always been happiest when absorbed in very detailed problem solving." (Tom – 'Work detail', Ed. 66: 10).

This theme highlights the importance of structure and routine in minimising stress for people on the autism spectrum. However, it also brings attention to the importance of these structures and routines being devised by individuals and not imposed on them by external forces. Indeed, externally imposed structures may be not be conducive to the lifestyles favoured by the writers in AU. Furthermore, when engaging in interests or addressing spiritual needs within these societal structures, ostracism may be experienced, perhaps explaining why people on the autism may describe desires to connect with others yet can highly value time spent alone.

Theme 2: Living with the consequences of an 'othered' identity:

The theme of 'living with the consequences of an 'othered' identity' referred to a large number of issues, categorised as societal othering, self-discovery and social navigation.

Societal othering:
Societal othering encompassed issues including being excluded from social activities, attempts of others to 'normalise behaviour', problems with authority figures (expectations of obedience and conformity), stigma and bullying.

Bullying was almost universally reported on as an experience at school life, it was also reported on as happening within the family, in Further and Higher education, and often within workplace environments. Living with such an 'othered' identity was also linked to feelings of isolation and social alienation, and mental ill-health such as social anxiety and depression. Many reported a sense of what could be described as 'psycho-emotional disablement' (Reeve, 2011, Milton and Lyte, 2012), between their own sense of self and the presentation of self expected from others:

> "Growing up in this way, it can lead to feeling as though we are "wrong" or "defective", and for me that led to low self-esteem and depression, as well as an intense need to find a way to improve myself and make myself acceptable to others." (Sian – 'Asperger's and anorexia', Ed. 68: 15).
>
> "Throughout my life I have developed an "act" to be "normal", which has allowed me to interact with people, but this negates the possibility of friendship due to the fact it's not the real me." (Robert – 'Relationships', Ed. 77: 16).

Unfortunately, despite a small number of contributors to AU talking of positive encounters and relationships with psych-professionals, interactions of this nature were often seen as extremely negative, with many reporting their needs were not recognised or were misinterpreted, with some saying that they were forced by such professionals into actions that they did not want. Others reported how they were blocked from seeing their families or made more ill by being under psychiatric surveillance, with one contributor to AU stating how one psychiatrist had labelled them as 'evil'.

> "I formed a high regard for all the therapists; however, none had experience of treating a person with AS so that, in some respects, their efforts were ineffective or even counter-productive." (Tony – 'Anxious thoughts', Ed. 76: 4).

Another source of difficulty associated with living with an othered identity was problems in gaining and sustaining employment. This was related to various issues, from one's thoughts being at odds with other people, not being able to achieve the qualifications that their ability warranted, being undervalued at work, a lack of job satisfaction, social alienation at work and underemployment through skills not being recognised.

> "I had the same to offer employers as other students looking for work, I was only ever offered the worst paid and hardest temporary positions in factories such as working in a noisy dairy or packing department whilst a friend landed office work." (Richard – 'The challenges of employment', Ed. 74: 12).

> "I work in retail, which is a notoriously pressured environment. It seems to proliferate with NTs who have no insight into their behaviour, let alone understand anyone else's." (Anon – Letter to editor, Ed. 75: 14).

Although some contributors to AU mentioned difficulties in terms of understanding the intentions of others within social interactions, it was far more common that a lack of understanding from others was of more difficulty, indicative of what Milton (2012; 2014) and Chown (2014) have previously theorised as the double empathy problem.

> "Yet NTs find it impossible to empathise with us." (Robert – Letter to Editor, Ed. 74: 9).

In the following passage there is also the problem of the 'dyspathic' (Cameron, 2012) reactions from others expressed:

> "Equally, if empathy is all about social alignment, it is not just about creating "Me and Us", but also about creating "Us and Them". It is normal for empathy to be selective, local, partial: typically people distribute their empathy in socially determined patterns." (Dinah Murray – 'Empathy – handle with care!", Ed. 76: 14).

Such interactions can lead to a downturn in trust and rapport with others and subsequent effects on feelings of wellbeing and belonging:

> "When I am in an environment I feel comfortable in, with people who are kind and tolerant, and doing things I enjoy, then I am as happy as the next person. It is when people tell me I should think, speak or behave differently that I start to feel different, upset, isolated and worthless. So surely the problem is a lack of fit with the environment rather than something inside my brain that needs to be fixed?" (Victoria – 'Are you taking something for it?', Ed. 76: 12).

Self-discovery:

A generally more positive aspect of living with an 'othered' identity for many contributors to AU was the influence of gaining a diagnosis. Many felt that this led to a greater sense of self-understanding and understanding of others. Issues remained for many though, for instance the perceived under-diagnosis of women, or a felt disjuncture between how an individual saw themselves and how others treated them.

> “The years of depression, cutting, starving and being sick were a reaction to a confused and anxious mind, trying to cope with being [an undiagnosed] Aspie in an NT world.” (Sian – ‘Asperger’s and anorexia’, Ed.68: 15).

In terms of personal identity, a diversity of views were expressed, from those wishing to not be defined by their ‘disability’ and who preferred to talk of ‘people with autism’ to those who saw autism as an inseparable part of their identity to be accepted and/or celebrated. Many also talked of having been on a personal journey, moving from hating ‘their autism’, to seeing themselves as a ‘person with autism’ to an ‘autistic person’, via their further engagement with autistic culture and community.

> “When I first learned about autism, I wanted nothing to do with it. Then, that led to me reluctantly accepting it just wasn’t going anywhere, and I called myself a person with autism. Now, though, I think of myself as an autistic person, with a family of other autistic people (even if we are far apart).” (Amanda – ‘Autscape’, Ed. 76: 14).

Most importantly, though, nearly all wanted to be able to define themselves on their own terms, and be better understood as an individual.

Social navigation:
This refers to the social practices needed to navigate a social environment when one has an, ‘othered’, or as Goffman (1963) would state: ‘spoiled identity’ and the management strategies available to people occupying such a social position. Many talked of finding safe and accepting social spaces within their lives in order to retreat from the social spaces where they felt ostracised:

> “Far from being loners, most of us are lonely.” (Ruth – ‘Relationships’, Ed. 77: 14).

> “I started attending a social group for people with autism. It has helped a great deal with my confidence.” (Paul – ‘Family on the spectrum’, Ed. 67: 20).

Others talked of how they needed to prepare themselves for tackling an unforgiving environment.

A large number of contributors to AU commented upon the issue of ‘masking’ or ‘passing as normal’. Some talked of a learnt performance of normalcy that they wished to break away from:

> “I was wondering how other people in the same position have “embraced” their Asperger’s personality and shed the masks that have to be worn every day – I feel that mine will have to be surgically removed, as they’ve grown to be a big but uncomfortable and ill-fitting part of me.” (Karen – Letter to Editor, Ed. 76: 20).

Others described how creating a facade of normality that subsumed their sense of authentic self resulted in psychological damage:

> "Help should be sought if mental-health problems are suspected, *but* I was diagnosed with depression when what was wrong with me was misguided attempts to conform to the norm." (Rob – Letter to editor, Ed. 75: 18).

Some contributors to AU rejected the need to pass as normal and instead promoted a sense of 'autistic pride':

> "We want to show people that autistic adults are autonomous; we want to speak for ourselves and we want to change the presumption that we need others to speak for us." (Kabie – 'The ARGH autism alert card', Ed. 68: 11).

Some talked of the minor advantages to passing within specific, but temporary social interactions:

> "The autistic spectrum is so wide that I know many of you will be reading this thinking, "Oh, I don't need social skills training", but some people do, especially around bullying." (Robyn Steward – 'Too sane for this world?', Ed. 76: 9).

This theme presents a complex and transactional challenge to developing positive and meaningful relationships between autistic and non-autistic individuals. Running through this is a thread that non-autistic people have difficulties understanding the viewpoints of autistic people, resulting in mistreatment such as bullying, social alienation and marginalization in healthcare and employment settings. It is perhaps unsurprising then that autistic individuals feel that developing trust and rapport is difficult to achieve, compounding these difficulties. However, the experience of receiving a diagnosis could be seen to counteract some of these negative experiences, resulting in more empathic understanding from others. The need to pathologise autism in order to receive acceptance by non-autistic people may, however, provide further evidence for the 'othering' and alienation experienced by people on the autism spectrum. The practice of 'masking' or 'passing as normal' could be viewed as a highly adaptive response to this: faced with either being ostracized for 'being different' or being 'accepted' by pathologising one's identity through a medical diagnosis, 'acting' in a way to avoid either of these outcomes seems a logical strategy.

Theme 3: Connection and recognition:

The third theme 'connection and recognition' pertains to when adults on the autistic spectrum had found a sense of connection and recognition with/from others, a sense of wellbeing and belonging, and better understanding of their subjective viewpoint from those around them.

Sharing:

Often commented upon was the need and/or satisfaction gained from the ability to share one's interests, often with 'like-minded' others. Indeed, this was the primary theme of the Pen Pal section of AU magazine and a number of articles.

> "I would like to speak to people my own age or a little bit older. I like to talk to people with similar interests." (Lyssa – Pen pal 113, Ed. 69: 9).
>
> "I cannot talk about my real experience of life to most people, because they wouldn't understand or be interested. That makes me feel, as the saying goes, "lonely in a room full of people" and I'm fed up with it. I would like to talk to caring, intelligent, honest people who understand Asperger's well and with whom I can talk openly. My hobbies include cycling, walking in the countryside, and rational thinking." (Daniel – 'Pen pal 95', Ed. 68: 7).

Highly valued by many was the opportunity to share with others identifying themselves as being on the autism spectrum. This included the use of online forums, the space provided by AU magazine itself, and particularly the opportunity to meet in-person with others on the autism spectrum. This included local social groups and conferences led by autistic people, in particular the annual Autscape conference.

Acceptance:
When 'autistic spaces' such as the Autscape conference were commented upon, the narrative soon altered significantly: where notions of mutual acceptance and empathy with others, feeling less isolated, building friendships, meeting new people, having control over the 'discourse', enjoyment of leisure activities, acceptance of difference, interaction aides, commonality and 'love', were all mentioned.

> "As in previous Autscapes, I found the spontaneous discussions to be even more interesting that the scheduled presentations, as the spontaneous discussions allowed me to get to know other autistics, to explore our commonalities and differences, and to somewhat quench my insatiable thirst for meeting other autistics and for building bridges." (Chen – 'Autscape 2011, Ed. 69: 17).
>
> "When I meet my people, I know, because I feel it. And my people were there at Autscape and the whole thing was imbued with love, expressed autistically, but love nonetheless...Autscape has meant I see my differences as part of the differences that make up the whole of humanity and as something to be celebrated, not something I need to get away from...there was no fear or ridicule. I had never before experienced such a feeling of coming home." (Amanda – 'Autscape', Ed. 76: 14).

Connections with others, having ones needs recognised, and feeling mutual acceptance was not limited however to autistic-led spaces alone. Individual contributors to AU magazine talked of other social spaces within their lives where such understanding was being achieved. However, what these quotes highlight is for the felt need for people on the autism spectrum to feel safe from fear and ridicule, to be valued for their contributions, creativity and effort, and to be acknowledged. This need can be seen as analogous with the notion of 'unconditional positive regard'. For some this meant the rejection of wellbeing and notions of belonging as defined by an 'ableist' or 'neurotypical' society.

This theme recognises the importance of feeling a connection to other 'like-minded' people for the well-being of people on the autism spectrum. Having this connection leads to feelings of acceptance and being understood which, as described in theme two, are feelings that many autistic people have not experienced when interacting with non-autistic people. These positive experiences of connectedness can result in feeling safe, being valued and being acknowledged, viewed by the contributors to AU as vital aspects of their wellbeing.

Theme 4: Relationships and advocacy

The final theme identified, 'relationships and advocacy', was concerned with friendships, intimate relationships and family. These were frequent areas of difficulty for the contributors to AU magazine, with a number of articles dedicated to this topic.

> "Now, close personal relationships and I have what you might call a nodding acquaintance. I usually manage one every ten years or so, on average." (Mark – 'Don't really go in for titles, best just read on', Ed. 76: 11).

External support:
Relationships with mentors and tutors were valued highly when working positively for an individual. Many commented on the need for advocacy support, or in achieving their goals in life. Positive experiences in relationships such as these were remarked upon as significantly helping with issues such as mental health.

Family and personal relationships:
A commonly cited sub-theme was that of family life. Accounts of relationships of family life varied greatly, but could be seen as having a marked effect on a participant's sense of wellbeing and belonging:

> "We're all positive and that positivity has helped us cope with everything in life. We're a strong unit: we help others and each other." (Paul – 'Family on the spectrum', Ed. 67:20).

Self-advocacy:
There were increasing accounts through AU magazine in recent years referring to self-advocacy, autistic rights, and the neurodiversity movement. Interestingly, earlier editions

tended to have invites to participate in research being conducted on autistic people, whilst a later edition however contained an advert for contributions to the 'Autonomy' journal (Autonomy, 2014), an academic journal led by an autistic editor. This can be seen as marking a changing engagement with knowledge production within the field of autism studies.

This theme represents the profound effects personal relationships can have on the wellbeing of people on the autism spectrum, both positive and negative. The growth of self-advocacy may suggest a positive shift is occurring in these relationships from the historical position of people with autism being 'done to' to more partnership working.

Reflexive analysis of the researchers' positionality

The first author is diagnosed as being on the autism spectrum, a father to an autistic son, and an academic and consultant within the field of autism. He is, therefore, deeply embedded in autistic culture and community. Some commentators may hold the view that being so close to the subject matter could have influenced the objectivity of the analysis. However, it could be argued that this positionality actually enabled a level of 'interactional expertise' with the experiences being expressed (Milton, 2014). In interpreting the texts, interactional expertise has provided a depth of understanding that might otherwise be unavailable and allowed an awareness of nuance that informed the interpretation of the texts. Despite the advantages of the first author's positionality in terms of the analysis conducted, a decision was taken to involve the second author in checking the interpretation and themes developed to introduce another perspective and reduce potential bias in interpretation. The second author is a children's occupational therapist who has experience working with children on the autism spectrum and their families. Previous attempts to understand wellbeing and experiences of belonging have, therefore, been as a clinician and, largely, from the perspectives of parents.

Despite excluding editions of AU magazine that included articles written by the first author, comments and references to them were found. It was humbling and motivating to observe one's own contribution to this growing culture. However, many of the challenges and barriers discussed were encountered with disheartening familiarity. It was also inspiring to read people's experiences and potentially help these stories to reach a wider audience.

Discussion

The themes identified in this study highlight the many barriers and challenges faced by people on the autism spectrum in achieving wellbeing and a sense of belonging. Many differing narratives have been analysed, but commonalities persist. The challenges to meeting personal needs, the impact of living with an 'othered' identity, the importance of connections with, and acceptance from, others, and issues related to relationships and advocacy. These issues were found to impact on social isolation, mental ill-health, and empowerment, constructs highly relevant to well-being and belonging, in the accounts analysed.

The findings from this study support those seen in previous research. The need for support networks and effective professional support were highlighted (Renty and Roeyers, 2006), as were the quality of relationships, or lack of such quality, along with issues affecting self-esteem and mental-health (Burgess and Gustein, 2007). These accounts however could be seen as partial, given the wide breadth of issues highlighted in this study. It is certainly the case that more research is needed with regard to an autistic 'friendly' environment (Billstedt et al. 2011), yet perhaps a good starting point for such research would be autistic-led social spaces such as Autscape.

The findings from this study also indicate that thinking of autistic wellbeing purely in terms of efforts to remediate the challenges faced by autistic people as if they are a set of 'deficits' is highly limited and potentially counterproductive (as many accounts spoke of needs unrecognised or misinterpreted by professionals). This would support wider criticisms of a medical model of autism, yet questions whether the terms of 'autism' and 'neurodiversity' always lead to negative consequences for people so identifying. Whilst internalising a medical model view of autism as part of one's self-identity can be potentially harmful, as argued by Timimi et al. (2011) and Runswick-Cole (2014), reclaiming the label and associated concepts, as well as connections made with people with similar dispositions can be beneficial.

The results from this study have highlighted similar issues to that of Robertson (2010), and would similarly suggest that the concept of 'neurodiversity' can help autistic and non-autistic people alike to focus on the diversity of needs people have, their strengths and interests as well as challenges. Many of the core domains suggested by Schalock (2000) were also highlighted in this study, and as Robertson (2010) suggests would make a good starting framework for analysing quality of life and wellbeing for autistic people. Such domains are not any different from the core domains of wellbeing for non-autistic people, so is there a need to develop new quality of life assessment tools relevant to the particular needs of autistic people (Billstedt et al. 2011)? Perhaps not, however, assumptions of what may help improve quality of life and wellbeing for autistic people based on remedial efforts to try and improve 'functioning' by non-autistic standards are likely to be misplaced. Perhaps standardised measures could be used without much adaptation, yet what interventions researchers explore in order to improve feelings of wellbeing in the perceptions of autistic people may need to focus on the personal constructions and interests of the autistic person, rather than being based on normative assumptions.

Autistic identities can be said to be constructed within a context of an uneven distribution of power, with a medicalised view of autistic difference and remediation often acting as a hindrance to feelings of wellbeing and belonging. Issues such as 'masking' and 'passing' become a conflicted discursive space, in which some feel that it is at times easier to conform (although with great difficulty), whereas others feel unable to do so, or perceive attempts to do so as inherently disabling.

The findings from this study raise questions regarding the validity of the mentalising theory of autism (Frith, 1989, Baron-Cohen, 1995), and to social skills training that does not take account of autistic dispositions and subjectivity. As with previous studies (Beardon and Edmonds, 2007; Milton and Giannadou, 2012), the lack of understanding from non-autistic people in recognising the needs of autistic people as perceived by autistic people, can have a seriously deleterious effect on wellbeing and self-esteem. Reducing the 'double empathy problem' (Milton, 2012; 2014; Chown, 2014) may mean raising autism 'awareness' based on the lived experiences of autistic people and the concept of 'neurodiversity' (Robertson, 2010), rather than purely medical model remedial explanations. People who are navigating their lives within such social / situational and discursive conditions have much to manage. The opportunities created by AU magazine itself, Autscape and other such autistic-led spaces are obviously beneficial to many, yet so are relationships that accept and celebrate one's way of being in the world, wherever such relationships are fostered and nurtured.

One possible problem in this study was, as previously mentioned, the influence of the social positionality and view of the researcher on the interpretation of the data. Some issues of wellbeing and belonging may have been considered too 'obvious' to a cultural insider. It is also important to note that contributions to AU magazine are selected by the editor, who also proposes potential themes for future issues, and therefore some of the data analysed in this project reflects an element of editorial selection.

Conclusion

This study sought to explore the meanings of wellbeing and social belonging for adults on the autism spectrum in an attempt to develop understanding about how to realistically achieve these. Employing an interpretivist approach, using thematic analysis to understand the accounts presented within AU, resulted in the identification of themes related to meeting personal needs within social settings; the impact of societal othering; finding connection and recognition; and managing relationships with friends and family. Whilst these themes highlighted many of the challenges faced by people on the autism spectrum in achieving well-being and belonging, they also indicated that thinking of autistic wellbeing purely in terms of efforts to remediate challenges is counterproductive. Moreover, reclaiming the label and associated concepts and making connections with people with similar dispositions can be beneficial.

The findings from this research may not be representative of the views and experiences of a wider constituency of adults on the autism spectrum, but do indicate potential issues and priorities of those within the autistic community who are verbally articulate, and as a group are likely to have experienced forms of social exclusion, or at least misinterpretation of their social experiences and felt needs (Milton, 2012; 2014). The results of this study are useful for those considering what, and how, to measure in terms of wellbeing for future studies.

This in turn could help inform practical approaches for supporting people on the autism spectrum in adult life. It must be remembered however, that this study is but a snapshot of expressions from a number of adults on the autism spectrum, and can only highlight a number of main themes and issues, which can somewhat disguise some of the nuances contained within individual personal stories.

This study has brought attention to the many commonalities in what contributes toward wellbeing for both autistic and non-autistic people. However, it has also highlighted the considerable differences in the barriers to achieving it. This study has demonstrated a need for less focus on remediation and more on limiting the social isolation of autistic people.

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