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Occupational identity and competence in autistic adults: An exploratory study

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ABSTRACT

Introduction: Perceived or actual inability to engage in meaningful activities or occupations can threaten occupational identity, the capacity to engage, self-efficacy, satisfaction with daily occupations and quality of life. The purpose of this study was to explore the lived experiences of engagement in occupations among autistic adults and how these experiences affected their occupational identity and competence.
Methods: An atypical qualitative research method used an existing blog and asynchronous email interviews to collect data. In Phase 1, 196 blog posts from an existing online group for autistic individuals were analysed. Five autistic adults who were group members participated in email interviews in Phase 2. Data were deductively analysed according to the themes of occupational identity and occupational competence.
Findings: A strong occupational identity supported occupational competence, within the unique abilities of individuals, to engage in meaningful occupations and meet performance expectations. This included using technology, advocating for autism awareness and a sense of control while enacting valued interests. Perceived challenges were meeting obligations, work expectations, financial independence, working with others, relationships, establishing routines, and managing environmental sensory triggers. These affected both occupational identity and competence.
Conclusion: Despite many challenges and a limited awareness of autism, a strong occupational identity encouraged competence in meaningful occupations. These findings can facilitate client-centred occupational therapy intervention.

Implications for practice

- Autistic adults were found to have a strong occupational identity and competence within roles where adaptations accommodated their occupational performance.
- The occupational identity and competence of autistic adults are affected by differences when engaging in some desired activities, which have the potential to result in occupational disruption, particularly in routines and social participation in society and at work.
- It is important for occupational therapists:
  - to explore the occupational identity and competence of autistic adults,
  - to support and facilitate environmental modification and other adaptations for successful engagement in the meaningful activities they need and want to do,
  - to improve quality of life and wellbeing.

INTRODUCTION

The neurodiversity model assumes that the difficulties which autistic individuals experience are not a disability but a variation of the intersection of the characteristics of the person, the environment and society[1]. Autistic individuals report neurodiversity in terms of differences in social communication and interaction skills with focused and immersive interests or behaviours. Thus, these individuals may experience more loneliness, greater psychological ill health and sensory processing issues[2]. Supporting autistic individuals

to achieve valued occupations within society, these differences should be addressed by being client-centred, a fundamental principle in the philosophy of occupational therapy[3]. This requires an approach to clients that aims "to realign power and ensure that intervention is both informed by, and relevant to the clients' lives, values, and priorities".[3:174] This approach requires exploration of the person's occupational profile and analysis of their occupational identity and competence to facilitate everyday activities (known as occupations) that they want to do and which give their life meaning and purpose[4]. Thus, understanding the person in terms of their *doing* (competence in what they do), *being* (engagement), *becoming* (potential to learn and engage in new activities or occupations), and *belonging* (interaction with others and the environment), informs their occupational identity[2]. The sense of occupational competence relates to successfully engaging in a range of meaningful activities by meeting performance expectations. This includes having a sense of control while enacting valued roles and interests in productive, satisfying daily routines and occupations that contribute to wellbeing[4].

Being and doing in meeting occupational demands and expectations, particularly with routines and roles that require doing with others and reflecting on relationships[5], may present difficulties for autistic individuals in expressing their occupational and wellbeing needs, perceptions and desires. Perceived or actual inability to engage in a meaningful occupation can threaten occupational identity, including the capacity to engage, sense of self-efficacy, satisfaction with activities, occupations and interests, and ultimately quality of life. Occupational therapists facilitate engagement in meaningful occupations, modify and reshape environments, influence the thinking and value systems within society so that diversity is valued[1]. Thus, it is critical to understand occupational identity and competence from the personal perspective of the client when providing services for autistic individuals, considering neurodiversity as an alternative to the traditional medical model of disability.

The purpose of this study was to explore the lived experiences of autistic individuals to understand the experienced meaning of occupations in their lives, affecting their perceived occupational identity and competence.

METHODS

A social constructivist worldview[6] was incorporated in the study, which proposed that all people have unique perceptions and experiences of the world in which they live, play and work, based on their social learning, life experiences and context. The principal researcher (first author) was aware that autistic individuals are reluctant to participate in research due to their life experience of being misunderstood, not heard and stigmatised. Therefore, an alternate research approach was followed to maximise the choice for involvement to enable participation according to personal preferences across the autism spectrum[7]. An atypical qualitative research methodology used blogging and email interviews to accommodate the social-communicative profile associated with people on the autism spectrum[8].

The use of blogs and email interviews was supported by recent research, based on an increase in the use of social networks by individuals with autism as a safe space for shared interests[9]. Wilson, Kenny and Dickson-Swift[10] reported that blogging/microblogging adds value to research in reaching geographically diverse participants, is a low-cost, almost instantaneous data collection process and has content that is characteristically descriptive, reflective, exploratory, and interpretative. Blog entries have been described as naturalistic data, which can be followed over time, thus maintaining an audit trail. These techniques were used by Petty et al.[11] to analyse data on loneliness in autistic individuals. Unlike other research, where blogs were created for autistic individuals and were later analysed[12], an existing blog where members communicated often in a safe and controlled space in terms of social anxiety and behavioural differences[13] was used.

Other electronic methods of data collection, such as asynchronous email interviews, are also considered robust, although more time-consuming, but give the researcher time to explore the issues at hand[14]. This methodology has been supported in other studies by Cummins et al.[15] and Chapman[16] and is well suited to qualitative research with autistic individuals. The atypical data collection process used provided alternative forms of communication that enabled the participants to voice their perspectives and lived experiences.

Research procedure

The principal researcher (first author) negotiated membership in an existing international Facebook group for autistic individuals over the age of 18 years, where communication with other members was through text. A request for the principal researcher to join the Facebook group was made by the group administrator and once all members provided permission, they gave signed consent via email for the blogs to be analysed for the study. A survey was used to recruit individuals for participation in Phase 2 of the study. Those who indicated they were willing to participate were sent emails detailing the information about the study. In this study, ethical care of a vulnerable group was considered to ensure they felt safe, respected and heard while participating[17]. This study was approved before commencement by the University of Witwatersrand Human Research Ethics Committee (medical) [M160752]. The approved information sheets and informed consent forms were sent as attachments in an email inviting participation in the study. Signed informed consent was obtained via email from the members for Phase 1 data collection. For the members of the blog who were involved in the email interviews, further informed consent was obtained and returned via email for their participation prior to the interviews. Pseudonyms were used to ensure anonymity and all research procedures adhered to all principles of the Helsinki Declaration[18].

Data were collected and analysed in two sequential phases, where the first phase informed the second phase. All data were stored in a secure online location.

Phase 1

In phase 1 the researcher sampled blog information on two topics: participation in occupations of daily living and the meaning or value of occupations in daily living as expressed by the participants. The positionality of the principal researcher in the Facebook group represented an intersubjective role and required reflexivity[19]. The first author was an accepted member of the blog, which captured the voices of the participants on topics of their choice without directing the narrative. She held dual positionality as an "insider" of the closed group, and shared the context, unspoken norms, and experiences of the closed group members. However, her role was that of an objective, critical listener or an "outsider" who did not participate in any of the group's activities. This allowed an intuitive, deep understanding of the blogging data and interpretation of the data from a structured analytical standpoint[20].

The data in the form of 196 pieces of blogged information were collected for six months during Phase 1, until no new topics were identified, and the data were saturated[21].

Phase 2

Phase 2 examined participants' perspectives[14] and their lived experiences of their daily activity participation in a neurotypical world and how these experiences influenced their occupational identity and feelings of competence. Purposeful sampling was used to recruit information-rich participants from the membership of the blog group to participate in this phase of the study. Those individuals who expressed interest and consented to participate completed a brief biographical questionnaire. The sample consisted of five autistic adults who were able to provide a personal reflection and describe their lived experience in their own unique way on the subject being reviewed.

Participants reviewed the information obtained in Phase 1 to verify the accuracy of the analysis on the meaning of occupations in their lives. With the principal researcher, they identified their experience of occupational participation from the data collected. Asynchronous email interviews were then conducted based on five wide-ranging questions formulated based on the analysis of Phase 1 which included what occupations were routinely done, which occupations they liked and did not like to do and which occupations were obligations. Once the responses were collected, probing questions were sent to the individuals to obtain thick, rich descriptions to ensure clarity as well as to encourage detailed answers. The principal researcher clarified any misunderstandings, rephrased questions and provided prompts to assist the participants in answering comprehensively. She was sensitive to participants' feelings, checking that participants were comfortable in providing answers. The asynchronous email interviews, while time-intensive, also allowed participants the time and space to respond in a way that was comfortable and not judgmental[14]. A psychologist was on standby throughout Phase 2 of the study to provide emotional support, although this service was not utilised.

Data analysis

The data from Phase 1 was analysed using text data, in the form of transcripts, using inductive thematic analysis for a clearer understanding of the importance of occupations in the participants' lives[22]. Themes were used to create open-ended questions for the Phase 2 interviews.

The data from Phase 2 included the text from the email interviews of the five participants. The data collected from the blogs and email interviews were combined and text data were initially manually analysed deductively using the concepts of occupational identity and occupational competence as described by Kielhofner in the Model of Human Occupation (MOHO)[4]. Data from both phases were thenanalysed using the MAXQDA[23] program to interpret the text, allowing for the alignment of codes[24], categories and themes[25]. Findings represent a mixing of data from Phase 1 and Phase 2 to create comprehensive themes.

Trustworthiness

Trustworthiness was achieved through triangulation, where inferences included in the blogs were converged with the answers and discussions obtained in the email interviews. These inferences were assessed in relation to each other and interpreted. Rich, thick descriptions contained the shared experiences of the autistic individuals and their different perspectives on the importance of occupations to each person were explored[26]. Member checking was also used to ascertain the accuracy of the Phase 1 data by reviewing themes extracted from the bogs. Open-ended questions used in Phase 2 were a reflection and elaboration of the strengths and weaknesses in occupational performance identified in Phase 1. To clarify bias, the principal researcher made use of journaling to bracket and had regular meetings with the research supervisor to ensure an objective view[17].

FINDINGS

Five participants with ASD from Africa, Korea, the United States of America (USA) and New Zealand took part in Phase 2. Four participants were female. Participants were diagnosed with a range of comorbid conditions, including ADHD and anxiety[27]. All the participants were employed. One worked as an occupational therapist, others worked in early childhood education, and an online developer or teacher. Two participants attended therapy with a psychologist or an occupational therapist (Table I, below).

Table I: Demographics of participants

	Age	Gender	Country	Interests	Highest Level of Education	Comorbidities and therapy
1	32	M	United States (USA)	travel golf work	Doctorate	
2	38	F	Korea (K)	reading, writing, classical music, yoga, culture, languages current affairs. travel	BMus Hons	Anxiety and ADHD, Depression, Allergies, Migraines Irritable bowel syndrome Psychologist twice a month and a mentor a
3	31	F	South Africa (SA)	autism activist religion	BA degree	Bipolar disorder Epilepsy Food intolerances Low serotonin. Mild asthma, hay fever, Insomnia, Irritable bowel syndrome Skin problems Cognitive behavioural therapy and occupational therapy
4	38	F	South Africa (SA)	art	Degree in prophetic ministry	ADHD
5	29	F	New Zealand (NZ)	autism activist religion	Certificate in Arts	ADHD, SPD,-auditory processing, Irlen Syndrome, Mild intellectual disability, PTSD Possible seizures

Two themes that emerged, namely *Occupational identity and Occupational competence,* based on the participants' experiences, are reported in this paper (Table II, below).

Table II: Theme and categories

Theme	Category	Code
Occupational identity "I want to be accepted as a human being. I have my own identity, but my diagnosis is part of me."	Perception of the environment	Sensory processing
		Adaptation, meltdowns
	Capacity	Different and individual
		Carers and support
	Satisfaction	Technology
	Roles	Advocacy
		Parenthood
	Routines	Unexpected change
	Obligations	Finding and maintaining work
		Financial stability
Occupational Competence "Believe you have a reasonable chance of doing something- keep trying until you can't try anymore. Sometimes it's that one more attempt that can lead you to success."	Fulfilling expectations	Communication- social and in the workplace
		Relationships
	Maintaining routine.	Need support
	Variety.	Meaningful interests
		Financial limitations
	Pursuing values	Work and study
		Social inclusion and friendships

Theme 1: Occupational Identity

The first theme captured the essence of the participants' experience of their occupational identity and individuality through the occupations in which they engaged, and which made them feel human, as opposed to a diagnosis. This is evidenced by their sense of pride in what they had achieved and their perceived capacity, as well as satisfaction with the occupations and the roles they wished to or did enact. Enacting routines and obligations were described as difficult, especially with social limitations and sensory processing problems.

Perception of the environment

Difficulties with sensory processing caused challenges in forming a strong occupational identity since it affected their perception of the environment. This influenced their ability to organise, interpret and respond to the essential information. Thus, their capacity to engage in essential everyday activities, such as communicating, showering and driving, required strategies to enable occupational performance.

"*Sensory sensitivity and sensory overload are a big struggle for me. I can share and think better when I am talking to someone if I make LESS eye contact than the "normal" person is required to do"…"I still find the sensation of water on my skin a both exhilarating and painful experience. I like swimming in the sea and in pools but showering and bathing are a struggle "…sensory problems also made it too difficult to drive.*"
(F,38,SA)

Participants reported dealing with their sensory sensitivity in their unique ways using a range of sensory strategies for visual and auditory input and heavy pressure.

"…well I like my weighted blanket and my weighted cat (not a real cat), swimming and the therapressure brush."
(F,29,NZ)

When the sensory experiences overwhelm autistic individuals, meltdowns result. The nature and severity of meltdowns differ, as to how participants manage their meltdowns.

"I have challenging behaviours and meltdowns so severe that I head bang and self-bite."
(F,29,NZ)
"One may not want to be touched at all during a meltdown; another will need a bear hug to stabilise the body system."
(F,38,SA)

Participants perceived that sensory overload needs accommodation in the workplace.

"One thing that would affect an autistic person in their working environment is the smells, sounds and lights in particular. The need to sometimes have a dark room to go to, to recover from the light and overstimulation, is necessary."
(F,38,SA)

Capacity

However, even with the differences described above, participants, when discussing their autistic identity in relation to their **capacity** in occupations, perceived that they had embraced their unique way of doing, knew what facilitated their ability to perform occupations successfully and had come to terms with being different.

"If I try to be what I am not, I will stumble for the rest of my life. I've learnt to embrace the things that make me different, instead of obsessing over them."

(F,31,SA)

"I am not separate from my autism; it is who I am. Some things I am not able to do unless certain things are in place before I start my autism is an "unseen" thing it makes me look like I am not different from the outside but the way I need to do things is VERY different from the inside!"

(F,38,SA)

They perceived that being 'normal' is a social construct. This embraced the idea that all people are created differently, and each person has capacities and abilities in varying degrees. One participant described how being badly treated has motivated her to rise above this unfair judgment.

"We are all different and are not and were not created the same."

(F,38,SA)

"I feel my blood boiling when someone calls me… a 'retard'.

(F,31,SA)

Three participants had carers to assist in performing activities of daily living. This facilitated participants in engaging in occupations since most carers did not judge their incapacity but calmly supported and guided them to achieve end goals and manage time as well as their lives.

"…I need full supervision and assistance and personal carers."

(F,29,NZ)

"I talk, she never judges me. She always remains calm. She helps me make good decisions by asking the right questions."

(F,38,K)

Unfortunately, not all carers provided the appropriate level of assistance and took over the tasks that could be accomplished with support, highlighting incapacity and negatively influencing their occupational identity.

"i feel they take over in areas i can do well and that can be frustrating. i need to be supervised, supported, but i need an element of independence as well."

(F,29,NZ)

Satisfaction

One activity in which all participants identified capacity and were satisfied with was the use of technology in assisting with communication, social networking and participating in social groups. Participants perceived it to be easier to relay messages and to offload burdening emotions online.

"Whenever I feel upset about something, I write emails. It helps to write it all down and send it. My emotions are very strong, so it helps to let off steam...Hooray for technology."

(F,38,K)

Although participants agreed that social media activities were beneficial and satisfying, for one participant, they caused distress and sadness.

"Social media is good and bad. It helps me connect with other autistics worldwide, but I am also inundated with pictures of happy families and couples. This makes me feel lonely."

(F,38,K)

Roles

The participants described roles as important to a positive occupational identity, such as being an advocate. They expressed the desire for understanding and used their voices to be heard to achieve acceptance.

"I have autism awareness shirts that I wear. …If I get the opportunity to go to a meeting where the government or journalists are, I try to bring up an issue that autistics need help with. I've been asked to a lot of public talks about autism over the years."

(F,31,SA)

One desired role that was rarely enacted was that of romantic relationships. However, having different abilities from neurotypicals, they doubted they would be able to find the right person. They felt that they did not have sufficient knowledge about sex and sexual relationships and needed to be educated to prevent them from being taken advantage of.

"I don't know if sex is different for autistics, but the specialists say I don't know enough to consent to sexual activity. But I often wonder, could I cope if the guy was moderate to severely autistic too?".

(F,29,NZ)

One participant believed the role of being a parent should be supported; however, not all participants valued this role.

"our government tends to take babies of autistic mothers that have high support needs and put them in foster care. i don't want to be a mother if I'm not supported to be a mother."

(F,29,NZ)

Routines

To enact roles, it is important that routines are followed. The participants mentioned that they struggle with this, especially when sudden changes happen without warning, but acknowledged this was a reality of life that they could not control.

"Embracing change when it happens it is hard. So, I just focus on doing the best I can each day."

(M,32,USA)

Obligations

Routines support meeting obligations**,** such as finding and keeping a job, which, for some participants, was challenging, affecting their occupational identity. They reported that even the initial job interview was daunting.

"Many ASD people also struggle with interviews."

(F,38,K)

Employers do not understand autism and the accommodations needed, like time out to manage sensory overload and work relationships, which makes it difficult for the individual to develop capacity and perform at their best.

"He said none of the staff are allowed to take time off work at any time. He said because I asked -he thinks I am not serious about working and won't be committed to the job. He refused to let me explain myself and did not want to understand me."

(F,31,SA)

Participants also felt that, as adults, they should support themselves financially and their inability to find and maintain suitable jobs affected their ability to meet all financial obligations.

"I have stress when I am not sure about finances because I need to use finances to help me get to places and pay for electricity, food and airtime to contact people."

(F,38,SA)

Theme 2: Occupational Competence

The second theme, occupational competence or successfully enacting occupations, supported the development of a strong occupational

identity when fulfilling expectations. Participants reported competence in a variety of activities within their interests, but their competence affected maintaining routines and participation in the valued social and work occupations.

Fulfilling expectations

Achieving occupational competence through fulfilling expectations**,** their own or those of others, was important. The participants perceived that when this meant compliance with stereotypical social and cultural norms, they often felt dismissed and unheard in terms of expectations.

"I think people should ask autistic people what they want, and let autistic people help each other, rather than decide what we need, and tell us what to do."
(F,38,K)

Experiences of communication expected by others within society and especially at work, were perceived as challenging. They emphasised that communication expectations from the neurotypical population should be flexible and adaptive to accommodate autistic individuals to avoid misunderstandings and an uncomfortable social environment being created.

"…and then the communication gap between autistic people and neuro-typical people who like things done a certain way. I wonder how many 'neuro-typical' people realise that the way that they communicate to other people who are 'not the same' can be confusing and sometimes very patronizing."
(F,38,SA)

"… society's perceptions of autistic individuals limit our ability to achieve and make us more disabled over time and give up hope on us ever achieving anything in life."
(F,29.NZ)

The participants suggested that once employers understand ASD, they should make the accommodations that the individuals need. How instructions are given can influence competence in the expectations for productivity

"I think you need a boss willing to listen and who is also able to adapt your working environment to get the best out of your skills. Communication that is done piece by piece and in a clear way and written down in a doable list if needed."
(F,38,SA)

The aspiration to work hard and to achieve competence should be encouraged by providing accommodations to support fair work practices. But participants reported having to make an extra effort to find their solutions to issues affecting their ability.

"My conditions have greatly hindered my work opportunities. I can't work in an open office, because there are too many distractions and noise for me to concentrate. I had to try even harder to be good at what I did. I read books on spelling, grammar, etc and my mother helped me. The situation did greatly decrease my self-esteem and made me frustrated, depressed and sometimes angry."
(F,31,SA)

Developing competence in social skills to meet personal expectations in building and maintaining relationships was seen as important. The participants indicated needing extra support when developing and maintaining relationships, but that trying to initiate or maintain relationships was positive.

"I feel that a key reason my social skills have improved is because I have a motivation to work hard at it. my support system won't build itself if I don't build relationships with people who might potentially support me. Of course, consistently getting positive feedback has helped. In the autism context, successes will breed confidence."
(M,32,USA)

Participants described that forming work relationships was stressful. Despite their difficulties in social situations, they reported that friendly relationships ensured a more conducive working environment.

Participant 4: *"Stress adds to the equation of challenging work environments and relationships."*
(F,38,SA)

Maintaining a routine

To achieve competence and meet their own and others' expectations, maintaining a daily routine is essential. Participants reported difficulty with this.

"For most people, setting an alarm, getting up, putting on a geyser, then having breakfast, showering, tidying up and taking the right things to work is quite an easy routine in the morning to follow. For most autistic people, this is not necessarily so true."
(F,38,SA)

They stressed the need for support to assist them in carrying out their routine occupations in a more efficient way.

"..with the personal cares I really struggle with remembering how to wash and in the order. I do have a visual aide, steps chart, but there are times I freeze up."
(F,29,NZ)

Variety

However, occupational competence in a variety of occupations was reported by all participants. Although autism is generally associated with having limited interests, it was clear that the participants in this study had a range of interests and their successful participation in these interests was used to assist with reducing stress and improving their quality of life.

"The things that I really love to do are knitting, researching autism particular genetics and nutrition and sensory issues and I love to write and i love my science studies and i love being a aunty, i love getting out in the outdoors and I love swimming and the movies and ten pin bowling."
(F,29,NZ)

"When I get the opportunity, I swim. It helps me a great deal by de-stressing me."
(F,31,SA)

Participation in a greater variety of activities and interests was limited by financial strain, which restricted the number of interests participants could engage in. Sometimes the inability to engage in interests as well as financial issues increased levels of stress and anxiety.

"I don't go out often with friends, but money prevents me from doing a lot of things right now."
(F,38,SA)

Pursuing values

Pursuing values was supported by engaging in occupations that the participants valued. Motivation to study and work hard, to be successful and make a life for themselves was valued. The participants sought jobs and university courses that matched their abilities and occupational strengths, as it gave a sense of purpose, which added meaning to their lives.

"I am looking for a new job that matches my skills better."
(F,38,SA)

Limited knowledge of autism in communities, amongst lecturers and employers impacted their university and workplace experience. They emphasised how awareness of ASD can assist individuals in achieving their goals when accommodations are tailored to their needs.

"the plan for my disability needs is stuff like I have note takers, separate exams, use of computer, sensory modulation, one on one in science lab, and allowed to do work at home etc. I've had to leave science labs cause of meltdowns lately. I've just been changed to a noise-friendly class. The lecturer was sorry that she didn't think of the sensory environment at the beginning of the semester."
(F,29,NZ)

A lack of social inclusion and abuse impacted their opportunity to achieve occupational competence, personal growth and self-worth in social participation. All participants valued inclusively doing with others on their terms. The participants reported having faced many barriers to social inclusion and had endured social rejection, which they experienced as extremely hurtful.

"Ever since I started mainstream school, I was bullied and teased. I was made to feel inferior, like something all the kids could walk over when they pleased. They would verbally abuse me. They would either refuse me verbally or walk off as soon as I approached them. I ended up sitting by myself at break in Matric. This did great damage to my self-esteem and my emotions. - I was not accepted as a person."
(F,31,SA)

One participant described how, although friends were valued, it was a struggle to form the friendships longed for, leading to negative feelings when these relationships did not last.

"I struggled to relate to other people my age…All I knew was that most of the time I had the opportunity to connect with people and develop friendships, I'd mess it up. Then I'd hate myself for it."
(F,31,SA)

DISCUSSION

This study considered the voices of autistic individuals as occupational beings, acknowledging their experience of those occupations which provide meaning, value to their lives and which they consider support their well-being[28]. The findings of this study recognised the individual differences reported by all five participants, reinforcing the need to understand each person's occupational profile. This emphasises the importance of a client-centred and collaborative approach in occupational therapy, so services are tailored to the life challenges in activities and participation[29].

Throughout this study, the aim was to understand how the meaning of occupation influenced the occupational identity and occupational competence of the participants. The positive view of a strong occupational identity was related to the participants' sense of self being expressed through individual agency and their way of doing and being and individual success or subjective engagement in chosen occupations[30]. The results of this study suggest that the participants are not significantly different from neurotypical individuals in terms of the occupations they find meaningful. Anthony et al. report that autistic individuals have the same number of occupations as neurotypical individuals, but these are more likely to be sensory-oriented rather than social[31]. However, their occupational identity and competence are affected by differences when engaging in some desired activities, which have the potential to result in occupational disruption[2], particularly in routines and social participation in society and at work.

The participants reflected on the differences between themselves and the neurotypical society that labels them as disabled and overlooks their abilities and needs, which Turnock et al[32]. described is due to discrimination or poor understanding of autism and visible autistic traits. Participants perceived their capacity and effectiveness in doing[4] emphasising their individuality through the concept of neurodiversity, since varied expectations of 'normal' resulted in stress and unsustainable occupational adaptation. The development of an occupational identity has been described as an ongoing process grounded in the habituation of familiar routines[4]. Sensory processing affected the participants' perception of the environment, compromising engagement in everyday activities since they struggled with modulating their senses and they experienced meltdowns, an involuntary autonomic nervous system response, when adapting to stressful situations. These challenges affected participation in desired or meaningful occupations due to social rejection and demands on performance that participants were unable to meet[33]. As adults, participants felt these difficulties affected their obligations and responsibilities to themselves and others.

It is therefore vital for autistic individuals to have input into creating environments that allow for productive engagement in occupations by dealing with each individual's unique sensory processing challenges [34]. These findings support the capabilities approach, which indicates that capability is not only limited by the capacity of the person but also by the opportunity to do, as well as the supports or constraints in the environment in which the person functions[35]. Environmental factors were reported to have a great impact on occupational identity development due to the lack of knowledge and acceptance of autism internationally[36].

All participants had experienced occupational injustice in the form of occupational deprivation, as they were unable to use their full capacity. This was due to external factors such as being bullied, excluded from participation in society and work, resulting in financial difficulties, which limited their experience in occupations and the development of their occupational identity[37]. The notion of "who you are unable to become, because of what you are excluded from doing,"[38:124] persisted through many of the participants' responses. While the participants perceived their limitations to their *capacity,* they expressed a desire to do more, highlighting the need for engagement in other occupations or *becoming*. The need for help from unjudgmental personal carers was identified as a positive influence on their occupational performance, allowing effective engagement in their occupations while functioning within their own defined capacity[39]. Urbistondo Cano emphasized training for personal carers to appreciate the capacity of the autistic individual and their identity and life experiences in their context[40].

The participants in this study were aware of their strengths in their occupational capacity and how aspects of autism required adaptations[36] in what they do. Participants suggested that the harmful consequences of discrimination can be overcome by embracing their abilities and staying true to themselves, according to McComas et al.[41] by considering individual preferences and skills that facilitate autonomy and self-determination while being aware of which occupations provide meaning in their lives. A strong occupational identity was described by participants in the role of an advocate for autism. They were proud of this role, which challenged the misconceptions that neurotypical individuals hold[30]. This concurs with Benget Nirje's belief[42] that one should rebel against being underestimated and not being allowed to make choices and be unheard[43]. Thus, reinforcing that *doing* and *being* as an autistic individual can result in positive outcomes and acceptance of their differences[2] by choosing how to live and deciding what occupations are meaningful to them individually[36].

Participants perceived success in *doing* as technology users created a strong occupational identity with a resultant sense of satisfaction. Technology allowed the participants to communicate with other people with ease while accommodating their sensory needs. There was less pressure to make eye contact, which reduces miscommunications and anxiety[44] and the opportunity for the expression of their thoughts, needs and ideas without using oral speech[45]. Technology provided opportunities for shared experiences, gaining friends[46] and as a form of entertainment. Hassrick et al.[46] however, reported, as did one of the participants, that social media is not always beneficial and may cause vulnerability and exploitation.

In terms of future roles, participants indicated they would like to be involved in romantic relationships but emphasised sex education to provide them with a sense of identity legitimacy, defined as "who one is" in an occupational role[47]. Most participants in the study were female and described difficulties associated with understanding sexuality, the responsibilities and performance of this occupation, making them feel excluded due to their autism. Belluzzo et al. found that sexual health among autistic individuals is affected by a lack of sexual knowledge with increased risk of victimisation. They suggest that sexual education and inclusive support are required for autistic individuals[48]. The participants also suggested that sex education would provide the opportunity to understand their sexual autonomy[49]. While identifying with the role of motherhood, achievement of this role was seen as difficult due to their financial and sensory challenges, inability to follow a routine and the need to be supported[50].

A central obligation expressed by participants was that of supporting themselves financially. All participants engaged in productive, regular work or furthering their education. For some, however, their occupational identity was affected as they perceived they were unable to fully live up to their potential[51]. Literature suggests employment opportunities for autistic individuals are limited due to their behavioural, social and communication challenges[52] and emphasised the importance of supported employment. Although participants perceived that supportive contexts were often lacking or inadequate in both work and education contexts, they had to overcome barriers independently to achieve success[53].

Thus, occupational competence and achievement are achieved through engaging successfully in valued activities[4]. The participants reported having internal motivation and goals, and a desire to be successful. Not meeting perceived expectations, particularly social standards, was perceived to result from inadequate understanding of their abilities by others[2]. Although one participant indicated communication and social skills, which can be improved, adaptations for these components proved to be a key factor in achieving competence in employment, including how job-related instructions were given[52]. The participants felt they had not been provided with the opportunity to fully meet job and study expectations, as they had experienced employers and lecturers who were not knowledgeable about autism[54]. The lack of suitable work opportunities for most participants impacted the expectation that they would support themselves financially. The lack of finances also limited engagement in other occupations they were expected or desired to do, which can lead to the experience of occupational imbalance[55].

Maintaining a consistent routine of behaviour in patterns to meet expectations and obligations is a feature of occupational competence[4]. Participants mentioned that following a set routine of occupational behaviour is not easy, especially prioritising tasks and deciding what is needed and important for the day. They also expressed the stress and frustration caused by changes in routine, which deviated from a specific habituated pattern[56] impacting daily activities[57]. Competence in individual leisure activities, with choices that limited social activities, however, allowed the participants to engage independently and allowed for the expression of creativity[4]. The leisure pursuits included fun, sport, as well as intellectual pursuits, providing them with the opportunity to rejuvenate, rest, destress and feel emotionally contained. This allowed a sense of empowerment and self-knowledge, providing a sense of ability, control, and fulfillment[58]. These attributes were then embedded in a strong occupational identity[59].

Based on experience, participants indicated other limitations to occupational identity in a value-based vision of the development of their occupational self [60]. The way the participants had been treated by others and their relationships with others in the past contributed to the way they internalised and managed their social roles[2]. The participants expressed feeling socially accepted, but their stress when interacting with people and their social challenges contributed to feelings of isolation, resulting in occupational alienation[61]. Findings of this study echo the autobiographies of autistic individuals, which found that a strong craving for social interaction is affected by their communication and sensory processing difficulties, resulting in social isolation[45]. The participants did, however, value inclusion in research into autism[62].

Limitations of the study

The study was limited to autistic individuals who all had a post-secondary qualification and a range of interests, and who were able to communicate effectively using email. While this was reflective of the members of the blog used in this study. This may not be reflective of many other autistic individuals and results may not be transferable. The majority of participants were female, which may have biased perceptions in terms of participation in occupations and other findings. All data collected was in a text format and while this reduced errors that may occur due to transcription of data, nonverbal cues and responses of participants could not be observed in the email interviews.

CONCLUSION

This study explored a client-centred view of occupational identity and competence from the perspective of autistic individuals. The methodology allowed for the engagement with participants in the research process for understanding the occupational limitations, experiences and needs of autistic individuals[63]. The participants have faced many occupational challenges in meeting their developmental goals and aspirations, but indicated they do have a strong occupational identity within their autistic identity, which has helped and encouraged them to be proud of who they are and what they have achieved. All the participants shared a willingness to rise above their challenges and to be competent in their occupations, although they still faced limitations in achieving everything they needed or wanted to do. These challenges further resulted in difficulties in meeting the obligations of adulthood, social interaction and relationships with others, affecting their occupational competence. The limited awareness of autism has impacted their ability to meet employment and financial expectations, and the support needed to enact desired roles[2].

Conflicts of interest

None to declare.

Author contributions

Arisha Magan and Lyndsay Koch conceptualized the study and Arisha Magan completed the data collection. Analysis of data was completed by Arisha Magan and Lyndsay Koch. The data were validated and the article conceptualized and by Denise Franzsen and Patricia Ann de Witt with all approving the final draft

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