

Exploring the experiences of individuals living with autism spectrum disorder about their worker role: The South African and Central United States contextual experience

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Received 16 November 2021

Revised 20 July 2022

Accepted 22 August 2022

Pre-press 14 October 2022

Published 22 November 2022

Abstract.

BACKGROUND: Individuals living with autism spectrum disorder (ASD) experience challenges when they enter the open labor market or competitive employment.

OBJECTIVE: The aim of the study is to explore the experiences of individuals living with ASD and the perceptions of health therapists with regard to establishing and maintaining the worker role.

METHODS: The data was collected through interviews with two groups of participants diagnosed with ASD working in the open market, and key informants from South Africa and central United States of America participated in the study.

RESULTS: The data were collected by means of descriptive qualitative research methods and analysed using thematic content analysis. Three themes emerged from the study. Theme one: Facilitation of integration into the workplace after work training; Theme two: A need for client-centred practice in matching the client's job to their interest; Theme three: Work enables a sense of normality.

CONCLUSION: In conclusion the study presented findings that were common among participants in both cities, especially the importance of exercising supported employment and client-centred practice in placing the individual with ASD in the workplace.

Keywords: Open labor market, autism, coping skills and strategies, meaning, vocational rehabilitation

1. Introduction

The transition of individuals with autism spectrum disorder (ASD) from a school environment to the work setting could be challenging, particularly when they need to find employment (Wehman et al.,

2012). Individuals with ASD experience challenges related to post-secondary employment (Shattuck et al., 2012). Some of the strengths that these individuals experience include having a special talent; being creative; having a good memory and determined nature. Difficulties experienced by individuals with ASD include communication problems; social interaction concerns; behavioural difficulties; a lack of understanding others' feelings; not being understood by others; not coping with a change in routine;

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not being independent within society; and difficulty concentrating (Dillenburger et al., 2013). Work for individuals with autism (including ASD) provides them with a sense of purpose and belonging because it allows them to engage in a routine and allows an opportunity to interact with a variety of people they would usually not interact with (Rosqvist & Keisu, 2012). In the United States of America, one third of individuals with autism are employed; however, a more recent study led by the United Nations reported that only 20% of individuals with autism (including ASD) are employed worldwide (Standifer, 2011; Ban, 2015). In South Africa, 1.2% of individuals with disabilities (including individuals with autism) are employed (Department of Labor, 2015). According to Schall, Wehman and McDonough (2012), a possible reason that individuals with ASD struggle to find employment could be due to a breakdown at the point of transitioning from skills training programs in schools to the skills required in the open labor market (competitive employment). According to Mavranouzouli (2014) and Nachman (2020), supportive employment and school to work transition programs are the most common programs used to enhance the work skills of individuals with ASD (Mavranouzouli, 2014). Supportive employment programs have shown success in enabling individuals with ASD to maintain employment in the open labor market or competitive employment for a long period of time (Taylor & Seltzer). However, the cost of the above programs has been identified as being very expensive (Mavranouzouli, 2014).

The findings of a systematic review completed by Abubakar et al. (2016), as well as a scoping review conducted by Franz et al. (2017), did not reveal a single study that focused on adults living with ASD in sub-Saharan Africa (including South Africa). They did identify a strong need for large-scale research programs, to improve the quality of life of individuals living with ASD. There are currently limited studies that have been conducted in central United States of America and South Africa with regards to ASD and the ability of adults to transition to the workplace. However, there are currently no studies that looked at the dual cultural experience of individuals living with ASD in two countries namely, the USA and South Africa. The State of Missouri in central United States of America and the City of Cape Town in South Africa are alike in that both cities have similar demographics in terms of being multi-cultural in population and infrastructure. The City of Columbia in the State of Missouri has a population of 126,254

individuals and the City of Cape Town has a population of 4,710,000 (United States Central Bureau, 2020; Cape Town Metro Area South Africa, 2020). Missouri and the City of Cape Town are similar in that both have a large number of persons with disabilities (PWD- including individuals living with autism) and that many of these individuals are unemployed. The unemployment rate for PWD in Missouri is 82% and in Cape Town, 68% (Persons with a Disability Labor Force Characteristics, 2020; National Council of and for Persons with Disabilities, 2020). Furthermore, these two cities have dedicated health and social systems that contribute to the early identification and skills training of individuals with ASD. Therefore, emanating from a long-standing partnership between Missouri University (USA) and the University of the Western Cape (South Africa), a research project that focused on the transition of individuals with ASD to the open labor market or competitive employment was initiated in 2018. To date, one article that focused on the transition of individuals with ASD to the South African open labor market was published (Soeker, 2020). The current article from this project focuses on the cross-cultural experiences of individuals with ASD about transitioning to their worker role in the open labor market or competitive employment. According to de Leeuw, Happé and Hoekstra (2020) it is imperative to explore the views of individuals with ASD in different contexts as the information obtained from cross cultural studies could assist in enhancing a rehabilitation programs.

1.1. Objective

The aim of the current study was to explore the experiences of individuals living with ASD and the perceptions of health therapists with regard to establishing and maintaining the worker role in the open labor market in cities in central United States of America and South Africa.

The specific objectives were:

- To explore the barriers that limits individuals with ASD in establishing and maintaining their worker role in the open labor market in cities in central United States of America and South Africa.
- To explore the facilitators that aid individuals with ASD in establishing and maintaining their worker role in the open labor market in cities in central United States of America and South Africa.

2. Materials and methods

2.1. Methodological approach

Qualitative researchers study topics in natural settings, interpreting phenomena in terms of the significance people bring to them (Denzin, 2005). The study was positioned in the qualitative paradigm and particularly an exploratory research approach was utilised. Exploratory research is defined as research that provides an in-depth understanding of a phenomenon on which little is known, in order to generate ideas and new insights for future research (Robson, 2002). In the current study an exploratory approach enabled the researcher to obtain detailed information about the meaning that individuals with ASD associate with their worker roles, particularly in transitioning to the open labor market (competitive employment).

2.2. Population and sampling

The participants were purposively sampled from the statistical records of Non-Governmental Organisations (NGOs) in central United States and South Africa. Purposive sampling was used because the researcher wanted to explore the specific experiences of individuals living with ASD who had successfully transitioned to open labor market employment. The inclusion and exclusion criteria are set out in Appendix A and Table 1. The authors selected participants that met the inclusion and exclusion criteria of the study. In particular the authors tried to ensure variation by recruiting both males and females to participate in the study, however this proved to be a limitation as not many female participants participated in this study. Although the researchers attempted to obtain at least 10 individuals with ASD to participate in the study from both cities, they obtained 10 individuals with ASD from the City of Cape Town and only obtain 6 individuals with ASD from the City of Columbia, who were willing to participate in the study during the study time frame.

2.3. Data collection

The researchers were health care professionals (for example: occupational therapists, a social worker and a medical doctor) who conducted semi-structured interviews with each group of participants in the study. Group one consisted of ten individuals with ASD and five key informants from South Africa. Group two consisted of six individuals with ASD and

four key informants from central United States participated in the study (see Table 1). The researchers had no prior contact with the participants. The names of the participants were obtained from the statistical records of NGOs and private as well as public employment programs. The researchers also made use of social media in order to invite participants to participate in the study. For example, an advert related to the recruitment of participants was placed on a popular autism website in both cities. The health therapists and managers at the NGOs, public/private employment programs and protective/sheltered employment workshops contacted the participants and informed them about the study, and then the participants were given the opportunity to contact the researchers themselves (see Appendix B). One, 40-60-minute semi-structured interviews were conducted with each one of the participants. The interviews were conducted with sixteen individuals with ASD and nine key informants collectively. In order to ensure consistency with regard to the semi structured interviews, both researchers used the same semi structured interview guide with its corresponding probes. If there were variations in terminology used, then this was made explicit in reflective discussions before and after conducting the semi structured interviews, example the researchers obtained consensus with each in the use of terms such as open labor market and competitive employment. Data saturation occurred when no new information was obtained from the semi structured interviews, after the interviews with the tenth participant no new information emerged from the data.

2.4. Data analysis and trustworthiness

The researchers used a data analysis method described by Braun and Clark (2006), who advocates the use of the following six steps. Step one, the researchers familiarised themselves with the transcribed semi structured interview data by reading the transcriptions several times. Each transcript was de-identified in that a pseudonym was used to replace the participants name. Information of interest were then recorded in the form of the researcher's thoughts related to the interview on the margins of the transcribed document (Braun & Clark, 2006). Step two consisted of coding the transcripts by means of highlighting a phrase or quotation that emphasised importance to the participant linked to the research study (Braun & Clark, 2006). Step three consisted of grouping or clustering similar codes together to form

Table 1
Demographics of the participants

<i>South African participants</i>						
Name	Gender	Race	Age	Diagnosis	Education	Work history
P1 (RD)	Male	White	44	ASD (mild), Marfan syndrome	Tertiary education (Masters)	Lecturer (information science)
P2 (LW)	Female	White	53	ASD (mild), ADHD	Tertiary education	Project manager
P3 (HG)	Male	White	21	ASD (mild), intellectual disability	High school Diploma	Dog day care
P4 (KL)	Male	White	34	Asperger's	Tertiary	Counting assistant (casino)
P5 (MN)	Male	White	30	ASD (mild)	High school	Stockroom assistant
P6 (EC)	Male	Coloured	25	ASD (mild)	High school diploma and massage therapist	General assistant in a bakery and sheltered employment
P7 (GG)	Female	White	30	ASD (mild)	High school diploma	Online student success manager
P8 (ZG)	Male	White	45	ASD (mild)	Diploma in IT	IT lab manager
P9 (LB)	Female	White	40	ASD (mild)	Diploma in hotel management and completed a secretarial course	General assistant in the hotel industry
P10 (EG)	Male	White	45	ASD (mild)	Tertiary level education (LSEN)	Tutor (university)
Key informants						
	Profession	Years of experience	Organisation			
K1	OT	4	NGO (Work for You)			
K2	OT	5	NGO (Work for You)			
K3	OT	3	NGO (Living Link)			
K4	OT	10	OT/Special needs educator			
K5	OT	5	NGO (Living Link)			
¹ Coloured race: The racial group termed coloured is defined as a person of mixed European ("black") or Asian ancestry, as officially defined by the South African government from 1950 to 1991 (South African History, 2019).						
<i>American Participants</i>						
Name	Gender	Race	Age	Diagnosis	Education	Work history
P1 (AK)	Male	White	26	Asperger's	High school diploma	Package delivery service
P2 (CC)	Male	White	21	ASD (mild)	High school diploma	IT
P3 (DK)	Male	White	20	ASD (mild)	High school diploma	Factory
P4 (KB)	Male	White	29	Asperger's	Bachelor's degree	IT
P5 (KW)	Male	White	20	ASD, intellectual disability	High school diploma	Grocery store (various tasks)
P6 (SMS)	Female	White	22	ASD (mild)	High school diploma	Restaurant (server and cleaner)
Key informants						
	Profession	Years of experience	Organisation			
K1	BCBA	13	Autism Centre			
K2	Program Director	10	State University			
K3	Job counsellor	10	Vocational rehabilitation			
K4	Teacher	2	Job skill program			

Table 2
Mind map of themes

Missouri research findings	
Theme one: Facilitation of integration into the workplace after work training	1.1 Category: Work-specific practical training modules 1.2 Category: Supported employment strategy
Theme two: A need for client-centred practice to match job to client's interest	2.1 Category: A need for more practice-related opportunities in the workplace 2.2 Category: Challenges related to the provision of multiple instruction
Theme three: Work enables a sense of normality	3.1 Category: Not being a burden to society 3.2 Category: Work provided a sense of security 3.3 Category: Familiarising employers and family members with regard to the work-related skills and interests of individuals with ASD

themes (Braun & Clark, 2006). Step four consisted of relating the identified themes with coded extracts and forming a thematic guide describing how the themes were formed (Braun & Clark, 2006). Step five consisted of finalising the names of themes and forming a general description of how the various themes links to each other in a flow diagram or pattern (Braun & Clark, 2006). Step six consisted of drafting a research report in order to disseminate the findings of the study (Braun & Clark, 2006). In the current study, the codes obtained from the transcripts, were grouped to form categories and themes (please see Table 2). The researchers used inductive analysis in order to allow themes to emerge from the findings of the study. The researchers, independently coded each transcript and then had a meeting in order to obtain consensus on the themes identified in the study. All authors obtained similar categories and themes that linked to the objectives of the current study. The above procedure served the purpose of intercoder reliability. In order to ensure the trustworthiness of the qualitative findings, the strategies advocated by Krefting (1991), namely credibility, transferability, dependability and confirmability were utilised. Credibility was ensured by the detailed description of the experiences of the research participants about adapting to their worker role. Transferability was ensured by the detailed description of the research methods, contexts of the where the participants worked, and using the exact quotes to describe the experiences of the participants. Dependability was ensured by means of detailed descriptions of the findings of the study, peer examination, and the triangulation of data (i.e. the experiences of both the individuals with ASD and the key informants were used in order to strengthen the findings of the study) (Krefting, 1991). The study was described in detail in order to allow the reader of the research report to follow an audit trail. The researchers drafted field notes related to their reflection on the methods used in the study as well as various decisions made while completing the study.

These research data were kept in electronic folders (Krefting, 1991). Confirmability was ensured by means of the use of a reflexive journal, in this journal the researchers reflected on their personal biases or assumptions related to the study (Krefting, 1991).

3. Results

Three main themes emerged from the analysis of the findings. The themes will be discussed in detail in the following section. Four of the participants from the City of Cape Town and five participants from the City of Columbia, had a high school level of education, however the high schools may have included work training programs. These programs are effective in providing the students with possible work-related skills that could enable them to transition to finding employment in various work placement settings such as sheltered employment and competitive employment settings.

3.1. Theme one: facilitation of integration into the workplace after work training

Theme one is characterised by the *facilitatory factors* that contributed to the individual with ASD adapting to their worker roles. The facilitatory factors such as work-specific training programs and supported employment strategies enabled the individual with ASD to adapt. The facilitators were explored through the following categories:

Category: “Work-specific practical training modules”. The above category described that work-specific training in school-to-work transition programs positively contributed to the ability of individuals with ASD in adapting to their worker roles. The category is described in terms of the following sub categories: “Inclusion of life skills, communication skills, information technology”.

The first sub category “Inclusion of life skills, communication skills and information technology” describes the contents of education curricula as being important in enabling the individual to live independently and prepare for professional work. One participant said:

“The training modules that we have in both include modules such as personal empowerment, personal hygiene, life skills. We also got a cooking module, so anything really that has to do with living independently. So, we say to them that you are going to live alone for..” (Key informant 1)

“Training program offered programing classes for IT, and database management. I also learned refresher information about IT that I... ..” (CC participant)

Another participant indicated that they did benefit from getting practical training on the requirements of the job that they were going to engage in. He said:

“They show you how to tag, they show you what’s steaming and stuff. They sort of give you instructions and with the stock room you need to have product knowledge so you need to know the products, so you get product knowledge training. But a lot the stuff is on the job, you learn it on the job.” (MN participant)

Category: “Supported employment strategy”.

The category is described in terms of “Independent living” and “Work test placement”. The participants in the current study felt that ongoing support in the workplace as well as partnerships between stakeholders such as health therapists, individuals with ASD, and employers were helpful in enabling individuals to adapt to their worker roles.

In the first sub category “Independent living” describes the participant’s view that the engagement in work-related tasks facilitated independent living in their communities as the participants could now be less dependent on families. One participant said:

“So, I could make enough money to live on my own one day and pay bills. Have spending money and feel like an adult.” (KW participant)

Another participant indicated that proving to himself to his family that he could work in the open labor market/competitive employment was seen as a measure of him taking care of himself or living independently. He said:

“I think for myself it is proof that I can be independent, showing my family that I can be independent. That I can function as a normal member of society. And also, for me it’s like a protection mechanism, well besides socialising, it’s a protection mechanism because my family says that if I can prove to be independent, then they will not institutionalise me (good). So, if you can’t live independently you could end up in place where you don’t want to be or a place where you don’t feel normal, you don’t fit in there. Everyone wants their independence; everyone wants to feel as if they can function and do things on their own.” (MN participant)

3.2. Theme two: a need for client-centred practice in matching job to client’s interest

Theme two describe the barriers that the clients experienced, particularly when transitioning to their worker role in the open labor market (competitive employment). The theme will be further described by the following two categories i.e., “A need for more practice-related opportunities in the workplace” and “Challenges related to the provision of multiple instructions”.

Category: “A need for more practice-related opportunities in the workplace”. The category is described by the following sub category: “Piecemeal type of work”.

The sub category, “Piecemeal type of work does not stimulate transferable work skill development”, describes that simple work-related tasks do not necessarily enhance an individual’s work skills, particularly if the work does not enable them to find work in the open labor market /competitive employment. One of the key informants indicated that she does not focus on work skills that might not be relevant, but rather on an individual with ASD’s language and social skills. She said:

“So, I don’t specifically do work skills (piecemeal type of work) but it (the program) focused on language development and the ability to read people. And learning about the abstract world. I had a young man once who literally looked out the window when I said it’s raining cats and dogs, so that he could see the cats and dogs fall from the sky. And I worked on their inflexibility as this sometimes hinders them a lot. So those are the aspects I worked on which they could use when they worked.” (Key informant)

Another participant indicated that some work activities he participated in can feel very simplistic or like step-by-step type of activities (i.e., piecemeal type of activities). He said:

“... . activities can feel a little piecemealed. Honestly, just trying to adapt to an office-like mentality. I'm still struggling with my mentality but I am overcoming it step-by-step.” (CC participant)

Category: “Challenges related to understanding multi-step instruction”. The category is described by the following sub category: “Abstract instructions”. The sub category “Abstract instructions” is described by some individuals with ASD as the challenges they experience in understanding abstract instructions. One participant said:

“Technically ... but have a hard time socially with others so we would teach those social skills as well. Emailing and being professional with tasks can be hard even though they can do the day-to-day skills or demonstrate the skills in class. Transferring them to the actual workplace isn't easy.” (Key informant)

Another participant said:

“Oh, and also arranging the tasks of whatever the job. So, when you explain to a neurotypical person you say this is the assignment, go do it. Usually for an autistic person you need to explain it step by step. So, when you lay out the steps you don't rush through it too much. And the autistic person may still ask why but when you ask the why questions a lot of people just brush you aside and that your just being stupid but actually the why helps you to do the task properly. People just don't understand.” (LB participant)

3.3. Theme three: work enables a sense of normality

Theme three explores the meaning that the participants relate to engagement in their worker role or work-related tasks. The theme highlights the views of the participants of internalising the social, economic and psychological benefits for successfully finding employment as well as maintaining employment. Theme three is discussed by means of the following categories, namely, Category one: “Not being a burden to society”, Category two: “Work provided a sense of security” and Category three:

“Work program needs to encompass a graded learning process”.

Category one: “Not being a burden to society”. Many of the participants felt that to be employed enabled them to make a meaningful contribution to society and not be a burden on family. The category is described by means of the sub category: “Participation in work enables one to socialise” describes the participants' view of the meaning they find in their worker role especially as work enables them to socialise with other co-workers and develop relationships. He said:

“Most the activities made me feel happier, fulfilled. I was glad to be there.

The bare bones honest answer... the world requires more me into money. A program also helps me have social situations - I need to be more social. It gives me more opportunities to do things I enjoy and helps me make connections for future opportunities.” (CC participant)

Category two: “Work provided a sense of security”. The category describes the meaning that the participants associated with the fact that they were no longer as dependent on family and social services in order to care for them financially. The category is described by the following sub category: “A sense of financial stability”, describes the happiness that the individual with ASD associated with being able to be employed and earn a salary. One participant said:

“Earning money and having a sense of purpose.” (JB- Missouri participant)

One participant indicated that participation in work tasks gave him a sense of independence, He said:

“Everyone wants their independence; everyone wants to feel as if they can function and do things on their own.” (MN participant)

Category three: “Familiarizing employers and family members with regard to the work-related skills and interests of individuals with ASD”. The category is described by the following sub category “ASD employer and family education sessions”. The sub category describes the need for employers and family to be educated on the functional abilities and interests of individuals with ASD. One participant said:

“Exposure and training for employers and the community, emphasis more on diversity-communication, communication, communication”. (AK- Missouri participant)

Another participant indicated how important it is to have the individual with ASD’s family understand their interests as this helps the individual with ASD internalise their worker role. The participant said:

“Hearing my client, really filtering through what their family supports think they’re good at vs what the client thinks they’re good and interested in. Freedom of choice and having the client list the pros and cons of different jobs”. (SMS participant)

4. Discussion

4.1. Barriers to employment in the open labor market or competitive employment

In the context of the current study the following barriers to employment were identified by both the key informants and individuals living with ASD, namely, Theme two: categories **“A need for more practice-related opportunities in the workplace”** and **“Challenges related to understanding multiple instruction”**.

A need for more practice-related opportunities in the workplace, was described by the participants’ view of piecemeal activities negatively affecting their work potential. The participants clearly indicated that these types of activities did not enhance their work skills so that they could be marketable in the open labor market/competitive employment. According to Sprent (2017), they indicate that most sheltered employment settings are subcontracted to complete simple processing activities. These workplaces are often paid for doing this work, however the work skill learned in these sheltered employment settings does not enable the workers to find and maintain employment. Most jobs in the open labor market require skills that are transferable, for example working as a cashier, assembly line work in a factory, and customer service. The main challenge relates to the individual with ASD’s communication and social skills; without these skills the individual with ASD struggles to adapt to the workplace.

The barrier **“Challenges related to understanding multiple instruction”** particularly with reference to the individual with ASD’s ability to engage

in work-related tasks. The participants in the current study highlighted the need to have employers understand some of the challenges they experience such as social awkwardness, understanding multiple instructions and communication difficulties. A study conducted by Soeker (2019) indicates the importance of employers understanding the abilities and potential of individuals with ASD, particularly highlighting a need to match the person’s skills to the job duties. Solomon (2020) further states that the understanding of the functional skills of individuals with ASD will enable employers to easily adapt the work environment of the employee with ASD. These findings also allude to the point that if the individual with ASD forms a working relationship with one-line manager, this may contribute to a more supportive environment for the individual with ASD. This type of relation or management strategy might enable the individual with ASD to reduce their anxiety, understand work tasks better, and ultimately be more productive in the workplace (Kenyon, 2015).

4.2. Facilitators related to employment in the open labor market or competitive employment

Theme one describes the facilitators in the current study, that include the categories **“Work-specific practical training modules”** and **“Supported employment strategies”**. The participants in the current study indicated a need for training whether in the form of education modules or training at the actual work site as a mechanism to enhance their ability to find paid work in the open labor market. According to Soeker (2020), in a study conducted with individuals with ASD in the South African setting, training in the skills required for employment in the open labor market is imperative for finding and maintaining employment among individuals with ASD. The job market is already saturated with able-bodied job seekers that makes it very difficult for individuals with ASD to compete and secure employment (Solomon, 2020). Therefore, developing work training programs for individuals with ASD needs to include market-related skills that are needed in the specific context where the individual lives. In the current study the key informants (health professionals) and individuals with ASD indicated that having ongoing support and job coaching in the workplace are essential for seeking and maintaining employment in the open labor market. The supportive employment strategy would also help in having the employer understand

the work skills of the employee. Wehman et al. (2012) reinforce the above sentiments, where they indicate that supportive employment strategies assist the individual with ASD, employers, co-workers, and other stakeholders to fully understand the ability of the individual with ASD and allows them to gain an understanding pertaining to which work tasks would suit the person with ASD best. Furthermore Wehman et al. (2016) indicated that customised supportive employment practices are very successful in enabling individuals with ASD to find and maintain employment. The authors also indicate that customised employment practices that enables the individual with ASD to choose a job based on their work interest enables individuals to main employment for longer periods of time. The participants in the current study were of the opinion that supported employment as well as working in jobs that was linked to their interest level and enabled them to maintain employment. This in turn enabled them to financially take care of themselves and their families. Furthermore, they felt that work test placement allowed them the opportunity to get a real work experience as part of the training program. Spreat (2017) indicated that the provision of practical work experience as part of a vocational rehabilitation program enabled a large percentage of individuals with ASD to find employment as well as maintain employment.

4.3. *Meaning that individuals with ASD experience*

Theme three of the current study describes the meaning that individuals with ASD experience, the theme is described by “*Not being a burden to society*” and “*Work that provides as sense of security*”. The participants in this study were of the opinion that they did not want to be a burden financially and socially to society. They wanted to engage in their worker role and earn a salary in order to take care of themselves and their families, thereby providing them with a sense of security. In a study conducted by Soeker and Pape (2019) that focused on individuals with Traumatic Brain Injury who returned to work in South Africa, they argued that individuals with disability strongly felt a need to take the responsibility for their lives by engaging in work-related tasks. The second category “*Work that provides a sense of security*” refers to the participation in work-related tasks that enables the individual with ASD to become aware that they could no longer rely on others to help them as they could manage their own needs. According to

Pallathra et al. (2018), motivational training programs enable individuals with disability to make independent decisions about their worker roles. Programs that enable the individual with ASD to choose a particular work environment that they would like to work in based on their interests, have a better chance of the individual maintaining their work over a longer period of time.

4.4. *Strategies to enhance work rehabilitation or skills training programs*

Theme three, category: “*Being educated on the requirements of the actual workplace in the work preparation programs*”, describes the characteristics of work rehabilitation programs that enable the successful integration of the individuals with ASD with their worker roles. The participants in the study indicated that the inclusion of training in real work tasks or market-related work such as computer-based work and factory-based work is essential for work training programs. The use of having skilled workers such as carpenters, app developers etc were seen as helpful as this allowed the individual with ASD to transfer their skills to jobs needed in the open labor market or competitive employment. Chappel and Somers (2010) indicated that having multiple work skills training could be very helpful particularly with a focus on social skills, effective communication skills and self-advocacy skills that could enhance the person with ASD’s ability to adapt and maintain employment in the open labor market/competitive employment. The sub category “***Work program needs to encompass a graded learning process***” describes the importance of having education sessions for both the employer and family of the individual with ASD. Lopez and Keenan (2014) and Chen et al. (2015) agree that if the employer and family are aware of the work-related challenges and the potential of the individual with ASD, then individuals with ASD have a better chance of adapting to both their roles in the community and work environment. Having a client-centred approach to training and placing individuals with ASD in the workplace greatly enhances their ability to be happy as well as to maintain employment in the open labor market or competitive employment.

4.5. *Similarities between the two groups of individuals living with ASD*

In the current study both groups of participants had undergone some form of work skills training

(e.g., some attended a formal schooling system that had a work skills training element, others attended a normal mainstream schooling system and some participants obtained a tertiary level qualification). The contextual information provided by the participants from central United States of America and South Africa, indicated that 100% of the participants in both groups were regarded as coming from a working class to middle class background, hence both groups of participants had similar contextual backgrounds. Furthermore, most of the participants in both groups were mainly working in manual labor related jobs. Regarding policies, there are favorable policies for people with disability including individuals with ASD in both countries. The Americans with Disabilities Act 1990 and the South African Employment Equity Act No. 55 of 1998 provide support for PWD in the workplace. However, despite having favourable policies in both countries, the employment rates for PWD continue to be low. Furthermore, in both cities there are active work placement agencies that utilise supportive employment principles in order to place individuals with disability such as ASD in suitable jobs in the open labor market. However due to the shortage of jobs for the general public it is challenging to find employment for all individuals with ASD.

4.6. *Differences between the two groups of individuals living with ASD*

The majority of the participants in both groups had a secondary level of education, however 60% of the participants from South Africa had a tertiary (university or college) level qualification and 17% of the participants with ASD from the USA had a tertiary level (university or college) qualification. The above difference could have impacted on the type of work that the participants could participate in, in the open labor market. The majority of the participants with ASD from the USA could find employment in the open labor market despite experiencing challenges with their worker roles. However, from a South African perspective although the majority of participants from the South African group of participants found employment, many struggled to maintain employment, possibly due to the general unemployment rate in South Africa possibly being higher than that in central United States of America. At the time of writing this article the unemployment rate in central United States of America was 5.7% (2020) and South Africa was 28.9% (2020). Cognisance needs

to be taken of the fact that despite the majority of the South African population being non-white, the majority of the participants in the current study were white (middle class) this means that the experiences of non-white individuals with ASD who may come from low socio-economic areas were underrepresented.

4.7. *Limitations of the study*

One major limitation is the fact that mainly male participants took part in this study. Another limitation of the study was the inherent limitations linked to qualitative research in that the findings of the study cannot be generalised as the aim of the study was to get an understanding of the experiences of individuals with ASD with regard to adapting to their worker role in two cities, particularly in Cape Town (South Africa) and Missouri (central United States of America). It is suggested that the qualitative findings of the current study be used to develop survey-based studies whereby a large number of participants could be recruited to participate in further studies with individuals living with ASD.

5. Conclusion

The significance of the current study is that it is the first study that explored the experiences of individuals with ASD and key informants such as occupational therapists in both central United States of America and South Africa. The study presented findings that were common among participants in both cities regardless of their different cultures and the contexts in which they received their work skills training as well as employment. The current study revealed that barriers existed particularly with regard to a lack of client-centredness in the training of the individual with ASD. The facilitators identified in this study included the use of work-specific practical training and having a supported employment strategy. The inclusion of life skills, communication skills, work test placement and work-related skills such as typing skills were viewed as enabling the individual in maintaining their worker roles. Finally, the study highlighted a need for work rehabilitation programs to not only focus on improving the individual with ASD's life skills such as communication and social skills but to strongly focus on work-related skills, possibly as early as possible example secondary school level. These strategies may enable individuals with ASD to find employment in the open labor mar-

ket. It could also be argued that there is a need for government officials to enforce employment equity policies in order to enable to opportunities specifically for individuals with ASD to find employment in the open labor market or competitive employment. A possible recommendation could be that both universities, namely the University of the Western Cape and the University of Missouri, facilitate “think tanks” together with state departments of labor and organisations representing people with disabilities to present the findings of this study, especially the barriers identified in the current study. The think tanks could be used as a measure to develop strategies to enhance skills training programs in order to provide individuals with ASD to find employment that is needed in South Africa and Missouri.

Acknowledgment

None to report.

Conflict of interest

None to report.

Ethics statement

The study was approved by the Institutional Review Boards (IRB) of the University of the Western Cape and the University of Missouri (IRB no. 2009359 HS and BMREC no. BM/17/4/3).

Funding

The project was funded by the University of Missouri and the University of the Western Cape research program (no fund number assigned).

Informed consent

The researchers ensured that the research participants were provided with information relating to the study. The participants provided written and verbal consent before participating in the study.

References

- Abubakar, A., Ssewanyana, D., & Newton, C.R. (2016). A systematic review of research on autism spectrum disorders in sub-Saharan Africa. *Behavioural Neurology*. <https://doi.org/10.1155/2016/3501910>
- Americans with Disability Act 1990*. <https://www.dol.gov/general/topic/disability/ada>
- Ban, K-M. (2015). Secretary-General's message for 2015. United Nations. <http://www.un.org/en/events/autismday/2015/sgmessage.shtml>
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research Psychology*, 3(77), 77-101.
- Cape Town Metro Area Population (2020). Population trends. Available online: <https://www.macrotrends.net/cities/22481/cape-town/population>
- Chappel, S.L., & Somers, B.C. (2010). Employing persons with autism spectrum disorders: A collaborative effort. *Journal of Vocational Rehabilitation*, 32(2), 117-124. <http://doi.org/10.3233/JVR-2010-0501>
- Chen, J.L., Leader, G., Sung, C., & Leahy, M. (2015). Trends in employment for individuals with autism spectrum disorder: A review of the research literature. *Review Journal of Autism and Developmental Disorders*, 2, 115-127. <http://doi.org/10.1007/s40489-014-0041-6>
- de Leeuw, A., Happé, F. & Hoekstra, R.A. (2020). A Conceptual Framework for Understanding the Cultural and Contextual Factors on Autism Across the Globe. *Autism Research*, 13(7), 1029-1050.
- Denzin N. (2005). *The sage handbook of qualitative research* (3rd ed.). California, USA: Sage Publications.
- Department of Labor. (2015). *Commission for employment equity, Annual Report 2014-2015*. [https://www.gov.za/Commission for Employment Equity Annual Report 2014-15](https://www.gov.za/Commission%20for%20Employment%20Equity%20Annual%20Report%202014-15)
- Dillenburg, K., Jordan, J., & McKerr, L. (2013). Autism spectrum disorder: public awareness and attitudes. *Research Update*, 84, 1-4.
- Employment Equity Act No 55 of 1998*. <https://www.laborguide.co.za/download-top/135-ee/pdf/file>
- Kenyon, L.M. (2015). Managing autism in the workplace. *Occupational Health: A Journal for Occupational Health Nurses*, 67(6), 18-20.
- Krefting, L. (1991). Rigour in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy*, 45(3), 214-222.
- López, B., & Keenan, L. (2014). Barriers to employment in autism: Future challenges to implementing the Adult Autism Strategy. *Autism Research Network*.
- Mavranzouli, I., Megnin-Viggars, O., Cheema, N., Howlin, P., Baron-Cohen, S., & Pilling, S. (2014). The cost-effectiveness of supported employment for adults with autism in the United Kingdom. *Autism: the International Journal of Research and Practice*, 18(8), 975-984. <https://doi.org/10.1177/1362361313505720>
- Nachman, B.R. (2020). Enhancing Transition Programming for College Students with Autism: A Systematic Literature Review. *Journal of Postsecondary Education and Disability*, 33(1), 81-95.
- National Council of and for Persons with Disabilities (2020). Available online: <https://ncpd.org.za/latest-articles/>

- Pallathra, A., Calkins, M.E., Parish-Morris, J., Maddox, B.B., Perez, L.S., Miller, J., Gur, R.C., Mandell, D.S., Schultz, R.T., & Brodtkin, E.S. (2018). Defining behavioral components of social functioning in adults with autism spectrum disorder as targets for treatment. *Autism Research, 11*, 488-502.
- Persons with a Disability Labor Force Characteristics (2020). Available online: <https://www.bls.gov/news.release/disabl.nr0.htm>
- Robson, C. (2002). *Real world research: A resource for social scientist and practitioner-researchers* (2nd ed.). Wiley.
- Rosqvist, H.B., & Keisu, B.I. (2012). Adaptation or recognition of the autistic subject? Reimagining autistic work life: Deconstructing the notion of "real jobs" in the Swedish autistic self-advocacy movement. *Journal of Vocational Rehabilitation, 37*(3), 203-212.
- Schall, C.M., Wehman, P., McDonough, L. (2012) Transition from School to Work for Students with Autism Spectrum Disorders: Understanding the Process and Achieving Better Outcomes February 2012. *Pediatric Clinics of North America, 59*(1), 189-202, xii Follow journal DOI: 10.1016/j.pcl.2011.10.009
- Shattuck, P.T., Narendorf, S.C., Cooper, B., Sterzing, P.R., Wagner, M., & Lounds Taylor, J. (2021). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics, 129*, 1042-1049.
- Soeker, M.S., & Pape, C. (2019). The use of the model of occupational self-efficacy for work retraining: A multiple case study. *Occupational Therapy International, 1*, 1-8. <https://doi.org/10.1155/2019/3867816>.
- Soeker, M.S., Truter, T., Van Wilgen, N., Khumalo, P., Smith, H. & Bezuidenhout, S. (2019) The experiences and perceptions of individuals diagnosed with schizophrenia regarding the challenges they experience to employment and coping strategies used in the open labor market in Cape Town, South Africa. *Work* (62), 221-231. DOI:10.3233/WOR-192857
- Soeker, M.S. (2020). A descriptive, qualitative study of the challenges that individuals with Autism Spectrum Disorder experience when transitioning from skills training programs into the open labor market in Cape Town, South Africa. *Work*, 2020. <https://content.iospress.com/articles/work/wor203127>
- Soeker, M.S., Hare, S. & van der Berg, J. (2021) The value of occupational therapy intervention for the worker roles of forensic mental healthcare users in Cape Town, South Africa. *Work*, 68(2), 399-414.
- South African History Online (2019). *Race and ethnicity in South Africa*. <https://www.sahistory.org.za/article/race-and-ethnicity-south-africa>
- Solomon, C. (2020). Autism and employment: Implications for employers and adults with ASD. *Journal of Autism and Developmental Disorders, 50*, 4209-4217. <https://doi.org/10.1007/s10803-020-04537-w>
- Spreat, S. (2017). Challenges of employment first. *Journal of Social Innovation*. <https://socialinnovationsjournal.org/sectors/89-government-policy-/2349-challenges-of-employment-first>
- Standifer, S. (2011). *Fact sheet on autism employment*. St. Louis, MO.
- Statistics South Africa (StatsSA). (2020). *Quarterly labor force survey (QLFS)*. <https://www.statssa.gov.za/?s=qlfs>
- Taylor, J.L. & Seltzer, M.M. (2011) Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism Developmental Disorders, 41*(5), 566-574. doi: 10.1007/s10803-010-1070-3. PMID: 20640591; PMCID: PMC3033449.
- United States: Census bureau (2020) Columbia Missouri statistics. Available online: <https://www.census.gov/quickfacts/fact/table/columbiacitymissouri/RHI225219>
- US Bureau of Labor Statistics. (2020). *Columbia, Missouri unemployment statistics*. https://www.bls.gov/eag/eag.mo-columbia_msa.htm
- Wehman, P., Lau, S., Molinelli A., Brook, V., Thomson, K., Moore, C., & West, M. (2012). Supported employment for young adults with autism spectrum disorder: Preliminary data. *Research and Practice for Persons with Severe Disabilities, 37*(3), 160-169. <https://doi.org/10.2511/027494812804153606>
- Wehman, P., Brooke, V., Brooke, A.M., Ham, W., Schall, C., McDonough, J., Lau, S., Seward, H. & Avellone, L. (2016). Employment for adults with autism spectrum disorders: A retrospective review of a customized employment approach. *Research Developmental Disabilities, 53-54*, 61-72. doi: 10.1016/j.ridd.2016.01.015. Epub 2016 Feb 6. PMID: 26855048.

Appendix A: Inclusion and exclusion criteria

Inclusion criteria:

- 1) The participants need to be 18-55 years of age; 2) Must have been employed in the open labor market for a period of 6-12 months; 3) The participants must be able to communicate in either English or Afrikaans; 4) The participants must be classified in the mild classification of ASD (the number and type of symptoms can differ drastically and range from mild to severe. Symptoms fall into a range of categories, including problems with social interaction, perseveration and somatosensory disturbance. This is also known as level 1 autism; they have mild symptoms and may not require much support)

Exclusion criteria

- Individuals with any other co-morbid conditions in conjunction with ASD, such as physical and mental impairments and psychiatric diagnosis will be excluded

Key informants

Below are the inclusion criteria pertaining to the Occupational Therapists and Providers of work skills services to individuals with disability or professionals working in the area of vocational rehabilitation:

- 1) The key informant is any professional with at least 6 months' experience in providing rehabilitative intervention to individuals with ASD. The key informants need to have experience of working in the field of vocational rehabilitation.

Appendix B: Interview schedule (adapted from Soeker, 2020)

Interview guide: Participants

1. Could you describe to me how you cope in your work environment? **Probe:** Describe what you do when you are in a stressful situation?
2. What factors within your working environment makes it difficult for you to cope? **Probe:** What

are the things that you find makes your job unpleasant?

3. Can you describe the support that you have when you feel that you are struggling to cope within your work environment? **Probe:** How do you make use of these supports? What type of support assists you within your workplace and at home? Do you feel you receive the support you need to cope within your workplace and at home?
4. Now that you have completed skills training and returned to work, can you describe how you have adapted to your work? **Probe:** Please describe how your role as a worker has been affected? Please describe your confidence in terms of overcoming the challenges in your job. Please describe your view of seeking another job in the open labor market.
5. Can you think of any ways that the skills training program that you participated in could be improved so that others attending it would be able to better adapt to working in the open labor market? **Probe:** Can you describe how the skills training that you received helped you to cope better within your work environment?

Interview guide: Key informants

- 1) Could you describe the main barriers and facilitators that affect the individual with ASD's work skills when working in the OLM. **Probe:** Describe the barriers and facilitators that specifically relates to individuals with ASD in maintaining employment.
- 2) Could you describe the components of a skills training program that helps facilitate the integration of individuals living with ASD in the OLM? **Probe:** Describe how you determine what needs to be focussed on for your clients in order to find employment? Describe how your rehabilitation differs from client to client?
- 3) Please describe how your skills training program prepares the individual with ASD to find employment in the OLM? **Probe:** What aspects of the program is important to enable individual's living with ASD ability to maintain employment? **Probe:** How does it help the client to adapt to the work environment?