The lived experiences of friendship of young adults on the autism spectrum.

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Dedication

With special dedication to my family

for their constant love and support.

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Abstract

This study explored the lived experiences of friendships of young adults with autism. The responses of the participants that focused on past and present experiences of friendships, provided an insight into their lived experiences as they lead their lives with autism. In addition, the study set out to challenge the validity of societal beliefs which state that persons with autism opt to stay in isolation.

This study adopted a qualitative approach and the conceptual framework used comprised phenomenology and the social model of disability. This study was also guided by the principles of emancipatory research. The research was carried out within the Maltese context and the participants were recruited through local organisations and, due to low response rate, through social media. Interpretative phenomenological analysis (IPA) was used as the methodological framework and data was generated through one-to-one, semi-structured interviews with five young adults with autism.

The participants' experience was marked by several paradoxes. Their responses reflected society's categorisation of their being deviant on account of their autism diagnosis even when the barriers experienced were mainly a result of that same society. The participants' responses reflected also an awareness of the stigma that their autism label holds in society, which ultimately influence the participantss self image. Thus, whilst the participants acknowledged their right for equal treatment in society, the manner in which they perceive themselves is negative and they are therefore happy to settle for less as long as they have friendly relationships.

This study provided an opportunity for the participants to make their voices heard in a society where their voices are very often silenced. Whilst the findings of this research provided a better insight into the lived experiences of the participants, further emancipatory research focusing on this topic is needed, especially within the local setting.

KEYWORDS: autism, young adults, friendships, lived experience, phenomenology, IPA, social model, emancipatory research

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CHAPTER 1

INTRODUCTION

Chapter 1 : Introduction

Research aims and questions

The study is entitled "The lived experiences of friendship of young adults on the autism spectrum". I have chosen to conduct this research following my continuous interest to study in depth the significance that young adults with autism attribute to the relationships formed with their friends. During my four years experience working with children and lately with adults on the autism spectrum, I have noticed a discrepancy between society's held beliefs and the experiences I have witnessed.

This study is therefore designed to explore the lived experiences of friendships of young adults on the autism spectrum and to explore the validity of common held beliefs in society stating that persons with autism prefer to stay in isolation (Gingell, 2012; Kanner, 1943 as cited in Locke, Ishijima, Kasari and London, 2010). The study focuses on the participants' childhood and young adulthood experiences and for the purpose of this research, the term "young adults" refers to persons whose ages range from eighteen to thirty-five years (Arnett, 2014).

Research about the lived experiences of friendships of persons with autism is rather sparse, especially within the local context, and thus this study provides an opportunity for persons with autism to voice themselves and in so doing enhance the readers' awareness. In order to gain insight into the understanding of the participants on how they perceive their friendships, the research questions adopted by this study are as follows:

> How are past and present experiences of friendships perceived by persons with autism?
>
> How do young adults with autism describe their past and present experiences of friendships?
>
> What factors contribute or hinder the relationships of young adults with autism and their friends?

Personal motivation for this study

My desire to explore the lived experiences of friendships of persons with autism stemmed specifically from the preoccupations of a mother whose daughter is on the autism spectrum, and who started to experience difficulties to maintain her friendships in the transition from primary to senior school. Frequently, I used to ask myself what was going on inside the adolescent girl's mind when she found herself alone during recreational periods and group activities. As such, I was interested to acquire a better understanding of the accounts of persons with autism themselves, as opposed to the way that others interpret their actions on account of their diagnosis. As a professional within the disability field, I hope that through this study the participants are provided with an opportunity to discuss their understanding of their experiences and, in so doing, a better apprehension of the multi-factorial aspects that inform their lived experiences is achieved.

Autism Spectrum Disorder

Autism Spectrum Disorder is a neuro-developmental disorder that is characterized by communication and language limitations, routine dependence and behavioural patterns (Klin et al, 2000). Most studies referred to in the literature review indicate also that persons with autism find difficulties in establishing and maintaining friendships (Klin et al, 2000; Rossetti, 2015; Potter, 2015).

Leo Kanner, a pioneer in autism research, believed that his patient children exhibiting autistic traits were born with an "innate inability to form the usual, biologically provided contact with people" (Kanner, 1943 as citied in Harris, 2018).

As the term "spectrum" suggests, individuals with autism have varying needs and as such should not be considered as a homogenous group of people. Given that the prevalence of autism is on the increase (Atadottir et al., 2015) many studies have focused on exploring this topic.

Friendships

The online Oxford English Dictionary (2019) defines a friend as "A person with whom one has developed a close and informal relationship of mutual trust and intimacy; (more generally) a close acquaintance". The presence of friends in one's life is believed to make life "more plausible, meaningful, and tolerable" (Albert and Brigante, 1962, p.33). A friendship is a relationship between two or more individuals who share mutual likes and interests. The element of choice in finding a friend is a crucial dynamic when establishing friendships whereby if a person is paid to be part of someone's life, that person cannot be considered a friend even though a close relationship may form from such obligatory role (Taylor and Bogdan, 1989 as citied in Rossetti, 2015). Furthermore, a friendship will come to an end if either of the individuals withdraws their attention and involvement.

Friendships are significant in a person's life and research by Myers (2000) suggests that persons with friends tend to lead a happier and more fulfilling life. However, despite the fact that friendships are believed to be beneficial in the course of a person's life, research by Locke, Ishijima, Kasari and London (2010) suggests that persons with autism have poor friendships "despite age and ability" (p.74). Potter (2015) contributes the difficulties experienced by persons with autism to establish and maintain friendships to an impairment that such individuals experience in their social skills, particularly their ability to empathise.

Conceptual framework

This study assumes that individuals with autism are the experts of their lived experiences as they hold first-hand knowledge about their experiences (Care Quality Commission, 2017). As explained below, phenomenology and the social model of disability were the conceptual frameworks used in this research, with interpretative phenomenological analysis (IPA) being used as the research method. This study is guided also by the principles of emancipatory research.

The Social Model of Disability

For many years, disability was perceived as an individual problem and for this reason people with disability have been subjected to several discriminations and injustices (Barnes & Mercer, 2010). Disability was equated with a burden and an illness to be cured. Disabled individuals were subjected to discrimination which did not result solely from the disabling barriers in society but also from the removal of basic human rights, as these individuals' lives were deemed unworthy, and still are in some parts of the world. The social model of disability knows its origin to persons with disability themselves and was introduced to defy the dominant views that perceived disability as a medical problem located within the individual (Swain & French, 2000). The social model initiated a shift in language and discourse from that of pity and tragedy pertaining to the individual, to discourse that located disability outside of the individual. (Foreman, 2005).

Phenomenology

As mentioned earlier, the other conceptual framework used in this study is phenomenology. The study of phenomenology owes its origins to Franz Brentano, whose main assumptions were to categorise the phenomenon as it is experienced as well as the types of consciousness. Most of Brentano's work was rejected by his successor, Edmund Husserl, who is considered to be the father of phenomenology. Martin Heidegger, is another significant person in phenomenology and, amongst other philosophers, developed further the study of phenomenology. As stated in Larkin and Thompson (2012), for Husserl, the study of phenomenology provided an objective way to study the everyday occurring phenomena through "bracketing" (p.102) in order to gain understanding about ones' *life-world.* Thus prior to the initiation of this research, it was necessary for me to put aside any predetermined ideas about the friendships of persons with autism in order to put my focus on the lived experiences of the participants.

Further to Husserl's ideologies, Heidegger focused on hermeneutics whereby the focus is placed on the meaning that the individuals attribute to their experience (Smith et al., 2009). As will be further discussed in Chapter 3, in his book *Being and Time*, Heidegger developed an extensive study about the experience of the being. This concept of being, or rather the Dasein, refers to the existence of the being of the individual in society (Moran, 2000). In this dissertation, Dasein will be used to refer to persons with autism. Heidegger considered also the experience of the individual - the Dasein - in relationship to the experience with others, what Heidegger called Mitsein.

In order to gain insight about the participants' lived experiences, Interpretative Phenomenological Analysis (IPA) was chosen as the methodological framework of this study. Five adults with autism participated in a semi-structured interview and answered questions about their lived experiences in relation to their friendships. An in-depth analysis was carried out following the interviews with the participants which led to the emergence of themes discussed further in chapters four and five.

Emancipatory research

As previously stated, this research acknowledges that the participants are the experts of their experiences and even though I could not abide by all the principles of emancipatory research, the principles were of valuable guidance throughout the research process.

Emancipatory research is based on six principles, developed by Stone and Priestly (1996), in the attempt of creating research that positively affects the lives of individuals with disability. Given my role as the researcher who has no disability, a continuous evaluation throughout the research process was made as a means to remain aligned with the standards and principles of this model. Through this approach, I enhanced the opportunity for the participants to voice themselves and, in so doing, kept their voices at the heart of the research whilst also relaying their position faithfully, as will be further discussed in Chapter 3.

Getting to know the participants

Aria is a 19-year old female on the autism spectrum, with a particular interest in make-up and sewing. Aria works part-time in a local shop and lives with her parents. She is also a full-time student at the University of Malta.

Clayton is a 37-year old male on the autism spectrum, married and currently waiting for his first born child. He enjoys computer games, TV series and history movies. Clayton recently moved to Malta from abroad and works from home.

Jon is a 25-year old male who lives with his parents and sister. With special interest in making new friends and travelling, Jon works part-time in maintenance and is involved in several communities such as Special Olympics, his local band club and local feast committee. Jon is on the autism spectrum and has an intellectual disability.

Nic is a 23-year old male on the autism spectrum. He is interested in computer and play-station gaming. Nic enjoys helping those around him with his advice. He works full-time in an office and lives with his parents.

Nora is a full-time student at the University of Malta. She is 20-years old and enjoys sports, particularly football. Nora enjoys reading and going out with her best friends. Nora is also on the autism spectrum.

Overview of Dissertation

This dissertation is divided into six chapters. Following this introductory chapter, the literature review presents an overview of the literature that explores the friendship experiences of children, adolescents and adults with autism.

Chapter 3 describes the methodological choices adopted in this research study. This includes descriptions about the research plan and conceptual framework as well as methods employed and ethical considerations. This chapter will also cover the strengths and limitations of the research methodology.

Chapters 4 covers the findings of the interviews held with the participants. The findings were divided into themes and will be presented in a separate chapter from the discussion so as to highlight the words of the participants as well as to give primacy to their voices. This chapter is followed by Chapter 5 which consists of the interpretation and discussion of the findings, supported by relevant literature on the subject.

This dissertation concludes with Chapter 6, which summarises the main findings of the study, putting forward a number of recommendations as well as some personal comments after the completion of the research journey.

Conclusion

This research explores the lived experiences of friendships of five adults with autism. This chapter outlined the research aims and objectives, personal motivation for this initiation of this study and a brief definition of the terminology applied throughout this dissertation. This chapter provided also a brief outline of the conceptual framework used. The next chapter provides an overview of the literature about the lived experiences of friendships of persons with autism.

CHAPTER 2

LITERATURE REVIEW

Chapter 2 : Literature review

The literature review will focus on the lived experiences of friendships of persons with autism from relevant published work and research literature. This research adopted a life course approach and hence will be referring to studies with participants of different age groups.

Introduction

Humans form interactions with others and through such interactions dependencies on other individuals are formed (Shockey, 2012). Although support is typically acquired from family members, persons outside the family such as colleagues and friends tend to facilitate the individual's personal growth (Larson, 1983) and overall well-being.

Friendships are meaningful relations that are freely chosen by the individual and thus a certain level of commitment is needed to establish and maintain the friendship. Successful friendships are based on shared interests and reciprocal respect (Rossetti, 2011). Rossetti's definition of what constitutes a successful friendship can prove problematic for individuals on the Autism Spectrum Disorder (ASD), as these individuals are believed to lack the necessary skills for successful social interactions and emotional reciprocity together with difficulties in empathy. In effect, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines autism as a developmental disorder comprising of communication deficits, restricted and repetitive behaviors (American Psychiatric Association, 2013). Furthermore, the DSM-5 diagnostic criteria enlist difficulties in social skills and interactions

Limited research has focused on friendships of persons on the autism spectrum and the research that does exist tends to focus on the experiences of children with autism despite the fact that difficulties in social interactions persevere in adulthood. In fact, existing research indicates that adults on the autism spectrum tend to face additional challenges that are not experienced by neuro-typical individuals (Mazurek, 2014; Moss, Mandy & Howlin, 2017).

This chapter explores the different experiences of persons with autism and their friends, as shown in existing literature. Although this study assumes that the individuals with autism are the experts of their experiences, the majority of research that exists on this topic was carried out with friends, parents and other relatives close to the person with autism. It is also worth mentioning that most of this literature attributes the difficulties that are experienced by individuals with autism with regards to their friendships to the deficits caused by the impairment with little or no consideration to the barriers that are caused by society.

Autism

The term autism was first coined by Leo Kanner in 1943 in his study about infantile autism. From his study with 11 children exhibiting "autistic disturbance of affective contact" (Kanner, 1943 as citied in Hobson, 1993, p. 2), Kanner concluded that these children were born with an "innate inability to form the usual, biologically provided contact with people" (Kanner, 1943, as citied in Harris, 2018, p.3). From his study, Kanner observed difficulties in communication and language, repetitive behaviour and rigidity in maintaining the same activities. Kanner emphasised also an "autistic aloneness" (Harris, 2018 as citied in Kanner, 1943) and the difficulties of these children to interact successfully with others.

Autism spectrum disorder is a life-long neurological disorder which as stated, is characterised by difficulties in communication, repetitive and rigid behaviour, social skills and interactions (American Psychiatric Association, 2013). Ultimately, autism affects the manner in which an individual makes sense, interprets and understands the world. Despite this closed definition of autism, it is important to note that no two individuals with autism are the same and as such it is important to consider each individual as a person first, with varying needs and desires, as other neuro-typical individuals.

Friendships

Friendships are typically depicted as close and intimate bonds between individuals (Bauminger et al, 2008; Bauminger& Shulman, 2003). Such bonds are based on reciprocal affection between the concerned individuals over a stable period of time. Friendships are significant in ones' life from early childhood when children learn significant social skills and experiences that aid in their development, social life (Bauminger et al, 2008; Bauminger & Shulman, 2003; Tsirgiotis, 2016; Rowley et al, 2012) and overall well-being.

Just as significant and important friendships are to one's quality of life, friendships also require particular abilities in understanding the perspective of others (Bauminger & Shulman, 2003). The research that is referred to in this literature review recognizes the difficulties experienced by persons with autism on account of the hurdles they encounter when connecting to other individuals, both socially and emotionally (Koning & Magill-Evans, 2001). As previously stated, the majority of research on the topic of friendships of persons with autism is done through children and adolescents. The social model of disability and phenomenology were therefore the conceptual frameworks used in the study, with interpretative phenomenological analysis (IPA) being used as the research methodology and thus research on the friendships of adults with autism is sparse. In addition, the majority of research on this topic is done with persons with autism who do not have intellectual disability in addition to autism, therefore the experiences that shall be discussed in this literature review are not to be considered common for all individuals with autism.

The research by Bauminger and Kasari (2000) explored the definition that children with autism give to friendships when compared with typically developing children. The participants' responses were divided into three categories which included "companionship, intimacy and affection" (p.450). From the results obtained in the study, Bauminger and Kasari (2000) argued that the definitions that were given by the children with autism were incomplete as they did not incorporate a comprehensive definition of friendship which includes "companionship, intimacy and affection", especially when compared with the responses of neuro-typical children. Bauminger and Kasari (2000) noted how the children with autism who participated in the study tended to focus more on companionship and less on affection and intimacy.

Further to the association of persons with autism with lack of affection and intimacy, loneliness and solitude are long held assumptions associated with persons with autism as shall be discussed further in the next section.

Loneliness and solitude

Despite the human need for social interaction and peer support, isolation and loneliness typify the daily lives of persons with autism. Difficulties that persons with autism encounter in social skills as well as their relationships with others have traditionally been ascribed to the deficits of the individual with autism (Locke et al, 2010) as has already been stated.

It is important to note the difference between the desire to be alone and having feelings of loneliness and isolation. Whilst feelings of loneliness are characterized by negative feelings which may be attributed to unsuccessful attempts to make friends or the lack of effective connections with others, solitude is characterized by a deliberate desire to be alone (Bauminger & Kasari, 2000), a desire which was first noted by Kanner (1943) in his research. Kanner's findings carried forward long held assumptions about the need and desire of persons with autism to keep their own company with minimal interactions with others, whilst attributing the difficulties experienced to the deficits of the individuals with no regard to the barriers caused by society.

Existing literature recognizes higher levels of isolation and solitude amongst adolescents and adults on the autism spectrum, due to their poor quality friendships (Rossetti, 2015; Mehling & Tasse, 2015; Potter, 2014; Muller et al, 2008; Mazurek, 2014). Consequently, such individuals are more prone to depression (Potter, 2014 & Mazurek, 2014) and anxiety (Mazurek, 2014). As such, the higher levels of depression and anxiety in persons with autism due to friendship of poor quality put into question the validity behind the reasoning that persons with autism choose to stay in isolation. However, although persons with autism are prone to experience higher levels of social anxiety, the study by Chen et al (2016) asserts that anxiety during social interactions is not experienced at all times and in all situations. Moreover, findings from Chen et al (2016) and Vine-Foggo and Webster (2017) with adolescent females with autism, affirm the satisfaction experienced by the individuals with autism following their interaction with others. These findings confirm that peer interaction is a "valued experience" (p. 1411) of the individual with autism, contradicting the validity of Kanner's arguments and findings that persons with autism exhibit a strong desire for "aloneness" (1943).

Bauminger and Kasari (2000) and Webster and Carter (2013) assert that the participants with autism in their respective studies reported having at least one friend. In their findings, Bauminger and Kasari (2000) reported that children with high-functioning autism aspired to be involved with friends, although it was noted that the quality of friendships between the children with autism and the other typically developing children differed as the children with autism in the study reported lower levels of "companionship, security, and help" (p.451). Notwithstanding the research by Bauminger and Kasari (2000), Hobson (1993) remarked that the social interactions of persons with autism tend to improve as the person grows older. Hobson noted that major difficulties in interaction are generally experienced with children rather than with adults. Difficulties in social competencies are considered as major obstacles in the development and maintenance of friendships (Potter, 2015) and the individuals' awareness of their limitations can contribute to higher level of anxiety when experiencing social interactions (Chen et al, 2016). It should also be acknowledged as a possibility that the increased levels of anxiety experienced by persons with autism result from added pressures created by society in order to "be productive and socially active" (Chen et al, 2016, p. 1410) and to successfully understand social cues. Furthermore, the findings from this research assert that anxiety is also likely to result from the apprehension of rejection by cherished and valued friends. Indeed, the study by Mazurek (2014) correlates higher levels of depressive and anxiety symptoms amongst adults with autism with loneliness. Mazurek (2014) asserts that negative experiences of friendships are more likely to impact the individual's self-esteem and overall satisfaction in life.

Friendship quality

As previously stated, autism is characterized by difficulties in language and communication. However, the severity of such difficulties varies according to the level of functioning of different persons with autism. Research about the experiences of friendships amongst persons with autism has generally focused on individuals with autism who at some point in their lives develop communication skills - such individuals were previously referred to as high functioning persons on the autism spectrum or individuals with Asperger's Syndrome.

Bauminger, Shulman and Agam (2003) found that whilst children with what is called "high-functioning" autism experience difficulties in friendships, the difficulties encountered by "low functioning" children with autism were more severe. In fact, the former were found to enjoy more social contact and peer-interaction than did the latter. Sigman and Ruskin (1999) affirm that, irrespective of the level of functioning, persons on the autism spectrum experience more difficulties in initiating friendships and play when compared with other children with disability and typically developing individuals.

In his research Myers (2000) claims that adults who have friends have been found to be happier than those without friendships. Further to the importance of having friends, it is perhaps of higher importance to have high quality friendships (Rossetti, 2015) and meaningful social interactions. High quality friendships have positive influences on the social and emotional well-being throughout an individual's life (Zhou, Li, Zhang & Zeng, 2012). The friendships of persons with autism differ from those of typically developing persons both in quality and quantity (Bauminger & Solomon, 2010; Lieb & Bohner, 2017). In the separate studies of Locke et al (2010) with adolescents and Bauminger and Kasari (2000) with children, the participants on the autism spectrum could successfully identify at least one best friend. However, in both studies, a discrepancy in the social involvement of the child with autism was noted when compared to other typically developing children. It is interesting to note that children with autism are reported to have lower quality friendships regardless of gender (Head, McGillivary and Stokes, 2014; Bauminger, Shulman & Agam, 2003) and age. Such realities are of concern especially because studies suggest that social interaction is vital for the individual's well-being (Tsirgiotis, 2016) and overall life satisfaction (Mazurek, 2014). Correspondingly, Lieb and Bohnert (2017) note how youths on the autism spectrum have higher rates of depressive symptoms than other typically developing individuals due to low quality friendships. These documented results indicate that not only are persons on the autism spectrum aware of the difficulties they encounter when initiating and maintaining a successful friendship but they are also not accepting of this reality and may become depressed from their failed attempts for successful friendships.

Vine Foggo and Webster (2017), in the study that was carried out with seven females on the autism spectrum aged between thirteen and seventeen years old, contradict the mentioned studies and argue that the participants in their study were able to maintain high quality and meaningful friendships. Similarly, Rossetti (2015) in his observational study of three groups of adolescence involving at least one individual with autism noted successful and high quality friendships. Through his observations, Rossetti (2015) claimed that the friendships he observed and the interactions amongst the participants involved were not discomfited or enforced. On the contrary, the participants and their friends seemed "to like each other, enjoy spending time together, and share an easy going rapport when together" (p.184).

Reciprocity of friendships

In the systematic review of twenty-four studies on the characteristics of persons with autism, Petrina, Carter and Stephenson (2014) noted that whilst children and adolescents with autism reported having friends, such friendships were not reciprocated by their peers. Similarly, the study by Rotheram-Fuller et al (2010) showed lower levels of acceptance of children with autism by their peers when compared to other typically developing individuals and the former had fewer reciprocal friends. Such studies indicate that, although children with autism are present in inclusive classrooms, they are nonetheless socially isolated from their peers. In the study by Calder, Hill and Pellicano (2013), twelve children with autism aged between nine to eleven years rated low satisfaction in the quality of their friendships when compared with the responses of the other neuro-typical children. Likewise, the research by O'Hagan and Hebron (2017) confirmed that as the child grows older, more difficulties are experienced as friendships tend to be less reciprocated. This study accentuated that as children with autism grow older they are further isolated due to their awareness of not being involved by others. Such results are confirmed also by Rotheram-Fuller et al (2010) who noted that children in early years were more included, accepted and hence had more fulfilling friendships than older students did. Similar results were obtained by Petrina, Carter, Stephenson and Sweller (2016) whose study suggested that children with autism had higher rates of reciprocal friendships when compared to earlier studies by other researchers.

It is interesting to note how students with more severe traits of autism and intellectual disability reported higher levels of friendships than did other children or adults diagnosed only with autism and whose friendships were not reciprocated (Rowley et al, 2012). Furthermore, Bauminger and Kasari (2000) noted how the children in their study reported having friends but these friendships were not verified by the children's parents or peers. This could potentially reflect a desire for friendships which is not reciprocated (Calder, Hill & Pellicano, 2013).

Activities enjoyed

In the study by O'Hagan and Hebron (2017), children with autism were found to spend more time engaging in solitary activities when compared with other typically developing children. The most enjoyed activities by the participants were watching TV or playing with their computer or board games. On the other hand, whilst playing board games and computers as well as watching TV were activities enjoyed by neuro-typical children, spending time with peers was a predominant activity enjoyed by neuro-typical children. Similar results were obtained in the study by Bauminger and Shulman (2003), whereby outdoor activities such shopping, studying with peers and eating out were amongst the favorite activities of neuro-typical children. Bauminger and Shulman (2003) noted how the friendships of persons with autism differed from those of neuro-typical children in number, duration of friendship and regularity of meetings. Furthermore, the mothers in Bauminger and Shulman (2003) accentuated the difficulties encountered by their children to initiate a friendship and that structured activities were found to be enjoyed more by children with autism.

Whilst ample studies have focused on the activities enjoyed by children with autism and their peers, fewer studies focused on the activities enjoyed by adults with autism. Amongst the limited studies that explored this topic is that by Orsmond et al (2013), with two hundred and thirty-five adolescents and adults with autism. As the study investigated the level of participation in social activities, the results indicated that the majority of activities enjoyed were typically done solitarily. Such activities included walking or exercise. Furthermore, activities which were scheduled in advance and which were facilitated by professionals or parents were amongst the most enjoyed activities by the participants in the study. On the other hand, socializing was rarely reported in this study. Such studies indicate that unfortunately, despite the fact that interactions are reported in childhood or adolescence, problems in maintaining friendships persevere in adulthood.

Empathy and emotional support

A deficit in empathy is believed to correlate with the difficulties that children and adults with autism experience in relation to their friendships (Schwenck et al, 2012). Friendship dynamics are likely to be characterised by reciprocity and the exchange of emotional support from all parties (Rosetti,2015). The ability to empathise is considered to be a crucial skill for the provision of adequate support and thus for a healthy and sustainable friendship. Individuals with autism have been perceived as having lack of warmth (Kuriki et al, 2016) and a decreased ability to empathise (McDonald & Messinger, 2012) with ultimate negative effects on friendships (Jamil, Gragg & DePape, 2017) and overall quality of life (Mehling & Tasse, 2015). Research by Mital (2011) and Schwenck et al (2012) suggests that persons with autism encounter difficulties in cognitive empathy, the ability to understand others' view points and emotion awareness. Conversely, Mital (2011) noted that whenever persons with autism are made "aware of others' states of mind" (p.S22), equal empathy is exhibited. Thus, the apparent lack of empathy that is highly associated with persons with autism may potentially be the result of emotional oversensitivity to others' reactions and assumptions that link persons with autism and lack of empathy may only be a coping mechanism to avoid painful feedback. Interestingly, Mital (2011) affirmed that "people with autism are oversensitive to the feelings of others rather than immune to them" (p. S22) and it is for this reason that they learn to "suppress".

Differences amongst males and females with autism

Although persons on the autism spectrum are often regarded as a homogenous group of people with similar characteristics, it is interesting to note the differences in experiences of friendships amongst males and females (Head, McGillivary & Stokes, 2014). The literature mentioned in this chapter consistently demonstrates that males are diagnosed with autism more commonly than females with a typical ratio of 4:1 (Tsirgiotis, 2016; Rivet & Matson, 2011; Lai et al, 2011).

Baron-Cohen and Wheelwright (2003) describe neuro-typical females as sensitive and emotional. Females tend to share their belongings as well as being better at communication than males. In their research study, Baron-Cohen and Wheelwright reported less aggression in females than males and noted a desire in females to build emotional connections with others once they reach teen-hood and continue doing so as they grow older. Head, McGillivary and Stokes (2014) also note that females are better at sharing their experiences with their peers with the ultimate desire to have close relations with others. In contrast, males tend to be more concerned with being popular and thus more competitive. As opposed to their female counterparts, males prefer to do things as opposed to communicate and tend to exhibit inferior social skills than females.

In the study by Head, McGillivary and Stokes (2014,) an apparent difference was noted in the friendship quality of male and female experiences of friendships. This study brought to light higher quality friendships in females rather than males. Head, McGillivary and Stokes (2014) assert that females on the autism spectrum tend to "superficially demonstrate better social and emotional skills than males with ASD" (p.1). Similarly, Attwood (2008), in a clinical description, asserts that females tend to develop coping skills in order to conceal their difficulties in social skills. This is mainly attained through imitation and memorizing of socially acceptable behaviour. On the other hand, the study by Daniel and Billingsley (2010) with seven boys with autism aged between ten to fourteen years old, demonstrated that mutual interest and activities were fundamental to the initiation and maintenance of their friendships. Daniel and Billingsley (2010) reported that in the absence of shared interests friendships are typically terminated. Head, McGillivary and Stokes (2014) assert that this behaviour corresponds to that of neuro-typical males, where the emphasis is placed on shared activities as opposed to social and emotional connections.

Education

The Salamanca Statement and Article 24 of the UN Convention on the Rights of Persons with Disabilities CRPD give emphasis to the right for general education for all (UNESCO, 1994).

Within the school environment, children are exposed to same aged children with whom they can form friendships outside of their families (Reohr, 1984). In this setting, children have the opportunity to learn social skills as well as an opportunity to cooperate with other same aged individuals (UNESCO, 1994). Through this practice, children build a sense of belonging which continues to positively reflect on the child's life as they get older (Rubin, 1980 as citied in Reohr, 1984).

Whilst there are some researchers in favour of inclusive education, others such as MacMillan, Gresham, & Forness (1996) and Sale & Carey (1995) argue that through this practice, children with disability are more likely to experience rejection and loneliness. The research study by Chamberlain, Kasari and Rotheram-Fuller (2007) aimed to answer the question of whether inclusive schooling is of higher benefit to the over-all wellbeing of children with disability with particular emphasis on children with autism. The study was carried out with 398 children in grades two through five in regular classrooms. Seventeen of these children with autism who did not have intellectual disability were referred to in the paper as children with high-functioning autism or Asperger's. The results from this research proved that children with autism scored lower in the social involvement of the classroom than other typically developing children in the research. However despite this result, none of the children that part-take the study were found to be isolated.

In relation to education and friendships, it is interesting to note that students with disability tend to spend more time with adults as opposed to other children without disability. In the next section this topic will be further discussed. It is important to note that most of the literature that exists on this topic focuses on adolescents.

Paid professionals and adult support in adolescence

Findings by Kuo et al (2011) and Orsmond and Kuo (2011) show that adolescents with autism tend to spend a considerable amount of time with paid professionals when compared with typically developing peers. For this reason, it can be argued that the dependence on adult and professional support further limits opportunities for peer interactions. Thus whilst support may be needed, the professional must not over support and is responsible to provide adequate opportunities for interactions and peer relationships (Kuo et al,2011). In consequence, whilst educators have opportunities to facilitate interactions from an early age, the mere presence of an adult educator within schools has the potential to obstruct peer interaction (Rossetti, 2011). Through an ethnographic means of data collection, Rossetti (2011) noted several missed opportunities for students with disability on account of adult interference. Rossetti (2011) wrote on how the students with disability in his studies were instructed to wait for their learning support educator once the lunch bell rings as the other neuro-typical children rushed to class. Through this observation, one can note that despite the educator's best intentions, the student with disability remains further isolated from the rest.

Social Anxiety

As previously stated, individuals with autism are reported to experience higher levels of social anxiety. Research by Gillott, Furniss and Walter (2001) found that children with autism aged eight to twelve years old suffered from higher levels of social anxiety when compared with other coeteaneaous children with disability and neuro-typical children. Similar findings were obtained in the separate studies of Bellini (2006) with forty adolescents on the autism spectrum and Kuusikko et al (2008), with fifty-four children and adolescents. The study by Kuusikko et al (2008) accentuated that as children with autism grow, they experience higher levels of social anxieties due to the acknowledgement and recognition of their differences.

Social anxiety can be defined as an intense fear of embarrassment or humiliation in social situations or public speaking (Bellini, 2006 & Kuusikko et al, 2008). As a matter of fact, social anxiety is a hallmark characteristic of persons on the autism spectrum and the difficulties that are experienced in such social situations are attributed towards the deficits of the individual with autism. Whilst it is important to determine factors that can help an individual to adapt better in social situations due to his or her diagnosis, it is of equal importance not to discount the obstacles that persons with autism experience on account of several disabling barriers in society.

Stigma

The research by Young (2015) with a group of teenagers with and without autism noted that stigma was exhibited by neuro-typical teenagers towards their peers with autism. Young (2015) puts forward a number of alternatives for this and starts by noting how persons with autism are less involved in extra-curricular activities, unlike their counterparts who use such activities to initiate new friendships. Young (2015) noted that teenagers with autism spend the majority of their time in solitude using technology rather than interacting with peers.

Similarly, the study by Gray (1993) noted that persons with autism are susceptible to higher levels of stigma than other persons with a visible disability such as physical disability. This is mainly because whilst one can easily note a wheelchair or crutch and hence can easily recognize the disability, one cannot recognize an individual with autism upon first glance just as easily. Thus when a deviation in behaviour is noted blame, or more specifically stigma, are directed towards the individual with autism. Similar results were obtained in the study by Butler and Gillis (2011) with adults. Like Gray (1993), Butler and Gillis (2011) attributed the higher levels of stigma associated with persons with autism to the atypical behaviors of persons with autism and the fact that no visible disability could be noticed at first glance.

As expected, higher levels of knowledge about autism contributed to less stigma. These were the results of the research study by Obeid et al in 2015 with three hundred and twenty-nine college students from Lebanon and three hundred forty-six college students from the USA. Furthermore, this study reported that females portrayed less stigmatizing attitudes than males towards their peers with autism.

Conclusion

This chapter presented a review of the literature about the lived experiences of friendships of persons with autism.

As has been noted throughout this section, the majority of the literature attributed the difficulties experienced to the innate deficits of having autism. Due to this, the low levels of friendship satisfaction and quality reported were most often attributed to the limitations of the individual with autism. Despite the social model and other progress made towards improving the quality of the lived experiences of persons with disability, the lives of these individuals continue to be hindered on account of their diagnosis . This is mainly due to the fact that societal barriers are not accorded the same level of importance as the impairment itself. The barriers that persons with autism experience to successfully maintain their relationships can lead them to withdrawal into more solitary activities which in turn, as seen in this chapter, are judged as choices made due to their diagnosis of autism.

The next chapter is the methodological chapter and will discuss the methodological choices made in this research study.

CHAPTER 3

METHODOLOGY

Chapter 3 : Methodology

This chapter focuses on the research plan including the rationale behind the choice of the theoretical framework and design of the research. It includes also a detailed explanation of the methodological choices, sampling strategy, how the data was analysed and ethical considerations. In addition, this chapter discusses the strengths and limitations of the study.

Introduction

An inability to develop meaningful friendships is a characteristic associated with individuals on the autism spectrum as has already been noted in more detail in the literature review. This research assumes that persons with autism are the experts of their experiences and as such, in order to obtain the best possible data and acquire the individual's viewpoints, the study was directed towards a phenomenological approach.

At the forefront of this research was the aim to determine how persons with autism establish and maintain their friendships and thus this research was guided by the principles of emancipatory research. An interest in seeking to understand the interpretation and meaning that individuals with autism attribute to their friendships encouraged the development and aim of this research. Contrary to the principles of the emancipatory framework, the research question did not originate from the participants themselves but stemmed from the preoccupations of a mother of an adolescent girl on the autism spectrum I used to support in learning. The concerns emerged when the girl began to experience difficulties in developing and maintaining friendships in the transition from middle school to senior school. As such, in spite of my aim to empower the research participants, this research cannot be considered fully "emancipatory" for the reason that "ownership" is not attributed to the disabled participants but rather to me as the non-disabled researcher (Stone & Priestley, 1996).

Conceptual framework

As has already been noted in the literature review, persons with autism, regardless of their age, tend to experience more difficulties than typically developing individuals to initiate and maintain meaningful friendships. It is important to note that, as opposed to most of the research referred to in the literature review that attributes such difficulties to the deficits of the individuals with autism, this research assumes that the difficulties experienced by persons with autism in initiating and maintaining friendships originate primarily from the lack of support by society. This research values the experience of persons with autism and this is what led to the topic selection and the choice of methodology. With these principles at the heart of the research, the social model (UPIAS, 1976) acted as a guide throughout the research process.

The social model of disability was introduced by persons with disability with the aim of defying the dominant views of the medical mode that located disability within the person (Swain & French, 2000). The social model is built upon the premise that disability does not result from the impairment of the individual but rather from an unendurable and indifferent society (Marks, 1997).

The other conceptual framework used in this study is the phenomenological approach. The study of phenomenology perceives reality through the lived experiences of the individuals being studied (Starks& Brown Trinidad, 2007). Particularly, phenomenology intends "to capture the meaning and common features, or essences, of an experience or event" (Starks & Brown Trinidad, 2007, p. 1374). Fundamentally, researchers who adopt a phenomenological approach aim to recognise important components that will make the phenomenon special and unique. This is achieved by the way in which individuals create meaning out of their experiences which is obtained when individuals talk about their life experiences and events (Pietkiewicz & Smith, 2012).

Phenomenology aims to "understand man, the thinker and actor of everyday experience, and this cannot be done without a return to, and description of man's existential situation" (Roche, 1973, p. 82). Thus, the aim of a phenomenological study is to acquire an understanding of the experiences as perceived from the individual's perspective; a reflection upon daily experiences to acquire an understanding of how the individual makes sense of reality.

Phenomenological research deals with "first-person accounts of life experiences" (Langdridge & Hagger-Johnson, 2009, p. 389). This was the fundamental component that influenced my choice of a phenomenological approach since several research studies have been conducted on autism but only a limited number have been based on the point of view and perception of the individuals with autism themselves. As a qualitative researcher, by adopting a phenomenological approach, my aim is to understand the meaning that individuals attribute to their life experiences. As opposed to other methodologies such as grounded theory and ethnographic research, whose aim is to understand events and behaviours in the natural context they appear in, phenomenology is more concerned with the meaning that the individual attributes to events or phenomena. In phenomenology, events are subjective and the same experiences can be perceived differently by different individuals. In this study, I do not aim to generate a theory or test a hypothesis but rather to gather the experiences of the participants and identify patterns in their responses in an attempt to understand the meaning attributed to their friendship experiences.

The ontological position in this study assumes that reality is subjective to the individual and the nature of reality is built from the individual's experiences. This study asserts that the individuals partaking in the research are the experts of their experiences, hence the epistemology in the study entails the interpretation of the individual's response through in-depth, semi-structured interviews with the participants.

Phenomenology

The phenomenological school of thought knows its origins to Franz Brentano. Brentano's main assumptions where "primarily concerned with classifying and categorising modes of experiencing and types of consciousness" (Roche, 1973, p. 2). However most of Brentano's work was rejected by his successor, Edmund Husserl. Husserl, considered to be the father of phenomenology, rejected the dominant methodology of his time and instead focused on the subjective experience as the foundation of knowledge. Husserl's pure phenomenology is regarded as the most important in his intellectual development. This acknowledgment is "ambiguous" as his successors do not "practise the specific reflective techniques of pure phenomenology" (Roche, 1973, p. 9). The "natural attitude" refers to the everyday truth illustrated in the beliefs that individuals hold in the development of daily lives. The "epoche" according to Husserl is the "meaningful conception" or the "essence" of the individual's experience, in other words that which is most meaningful in the individual's experiences (Roche, 1973, pp. 11,13). Essentially, it is assumed that the "studying of the conscious activity of the experiencer" cannot be distinguished from the individual's "experiences" (Roche, 1973, pp. 34,35) .

Martin Heidegger, another influential name in phenomenology, introduced the "sense of Being" (Roche, 1973, p. 284). This being refers to the individual's abilities to make sense of the existence in relation to the world around him. As explained in Chapter 1, Heidegger referred to the human being or more specifically the "being-in-the-world" as Dasein. Heidegger discussed the being-in-the- world in relation to the being-with, a concept which he referred to as Mitsein. Heidegger's concepts of Dasein and Mitsein were used in the study to explore and better understand the lived experiences of friendships of the participants.

Interpretative Phenomenological Analysis (IPA)

In order to adhere to the phenomenological principles, Interpretative Phenomenological Analysis (IPA) was chosen for the analysis of this research. The study of IPA explores an in-depth examination of the individual's personal interpretation and understanding of their life experiences and events (Smith & Osborn, 2008).

The description that the participants give of their experiences reflects their interpretation of those same experiences. Through this process, the researcher is involved in an active role in the attempt to interpret and understand what is being said by the participant. At the same time, an IPA approach takes into account the researcher's own interpretations which are influenced by his/her own conceptions of what is being said by the research participants, a process referred to as "double hermeneutic". The double hermeneutic process was applied in this research through continuous readings of the transcripts in order to better understand the standpoint of the participants whilst becoming familiar with their experiences. As per IPA procedure, the responses of the participants were grouped in themes that emerged from the interview process (Smith, Flowers & Larkin, 2009).

As stated above, the initial stage of the analysis involved repetitive readings of the transcripts as well as note taking about my personal interpretations of their meaning and reflections that emerged from the interview process. The focus at this stage of the research was to understand what the participants said and the meaning behind their responses. Subsequently the participants' responses were grouped in themes in order to achieve a more abstract understanding of the participants' accounts (Pietkiewicz and Smith, 2012).

Research Methods

The study made use of in-depth, semi-structured interviews. In keeping with the principles of IPA, the aim for this study to obtain a complete picture of the participants' experiences, hence the number of participants was limited to six. This is mainly because as previously stated, the interviews required to be very detailed in nature. The emphasis in this research is directed towards the individual rather than the "universal" (Pietkiewicz & Smith, 2012).

As per IPA procedure, purposive sampling was the method of choice employed in this research in order to ensure the recruitment of a homogenous sample group. This method is used in IPA so that the research question makes sense to the recruited participants (Smith and Osborn, 2009). An invitation letter was sent to Aġenzija Sapport, Autism Parents Association and Equal Partners Foundation in order to invite their service users to participate in this research study. However, due to limited response from the service users of the mentioned organisations, social media was also utilised to recruit any interested individuals, and the inclusion criteria were extended to individuals with autism up to forty years of age. Initially, the aim was to recruit six participants: three males and three females with autism aged between eighteen to thirty-five years old. However, only five individuals – three males and two females–showed their interest to participate in the study.

Procedure

The interviews took place at a location chosen by the participants. This was mainly at the participants' respective homes and at the University of Malta. This approach accorded the participants the adequate level of privacy to talk about intimate and private life experiences. The participants were encouraged to utilise any photos, diaries or other relevant material to aid in their responses during the interview. The participants were also re-informed that the interview was recorded in order to be transcribed word by word at a later stage.

Prior to the initiation of the interview, a detailed explanation of the aim of the interview and research was given to the participants. The participants were encouraged to ask any questions related to the study and interview process. This was followed by signing the consent form. The participants were presented with the option of speaking in English or Maltese and each interview lasted between thirty to forty-five minutes. Following the interviews, a word for word transcription was carried out for analytical purposes.

Ethical considerations

Prior to the commencement of this research, approval from the Faculty's research committee was sought. In addition, information sheets were sent to the local organisations approached in order to have their permission to conduct the interviews with their service users. Initial contact with the participants was made after ethical approval was granted. Information letters in three formats namely Maltese, English and easy-to-read Maltese and English were prepared and sent to potential participants via their respective organisations. Two of the participants who made contact through social media were provided with the information sheets directly from me. Copies of these documents can be found in the appendices of this dissertation.

In order to ensure anonymity, pseudonyms were assigned to each of the participants and any detailed information that could reveal the identity of the individual was removed. The participants were informed that they could withdraw from the interview at any stage during the process. In addition, the contact details of a psychological service was obtained and kept handy in case of need. These considerations were not utilised as the participants expressed their gratitude for being provided with the opportunity to make their voices heard. The audio tapes and transcripts of the interviews were kept in a private and locked cabinet and were only accessible to myself. Upon completion of the research, destruction of the audio tapes will be carried out as agreed with the participants.

In order to uphold the principles of emancipatory research, the participants received copies of the transcripts and were encouraged to provide any further comments or corrections.

Dissemination of Findings

Once this research is completed, the findings will be sent to the participants, local organisations within the disability sector and local schools. This will be achieved by compiling the research findings into a booklet with the involvement of the research participants themselves. For this purpose meetings with the participants to discuss the content of the booklet will be held. This method will be employed so as to ensure that the participants' voices are heard with the intention of increasing awareness about autism and in so doing, reducing pervasive stereotypical beliefs that continue to influence the lived experiences of the individuals with autism.

Strengths and Limitations of the Study

At the forefront of this study's strengths is the aim by which this study originated. This research provided a safe space for the participants to talk about pertinent issues in their lives without any judgement. Through the use of interpretative phenomenological analysis (IPA), focus was tuned to the interpretation that the individuals with autism gave to their experience. This offered a better understanding of the participants' standpoint of events and an opportunity for the participants to tell their side of the story. The participants were accorded a voice that is most often silent in today's society, as has been noted earlier on and in more detail in the literature review. Through the interview process as opposed to other methods such as a questionnaire, a rapport with the participants was established which is believed to have made the participants more at ease to divulge any personal information.

However, even though guidance from the principles of emancipatory research was sought, these principles could have been developed better through the use of more meetings with the participants or through joint ownership of the research design. Furthermore, the questions that led the interviews were completed by me and as such issues that were discussed during the interviews may have not been as pertinent to the lives of the participants as originally planned. Having said this, the fact that the interview was semi-structured in nature provided opportunity for the participants to diverge into any other relevant topics related to the friendship experiences.

The responses of the participants, whilst rich and meaningful in themselves, could not be generalised to all persons with autism. Furthermore, as a prerequisite of participation the participants required the ability to be verbal and as such the experiences of the participants that participated in this research can potentially vary from those of other non-verbal individuals with autism.

Conclusion

This chapter presented in detail the rationale behind the methodological choices made throughout the research process. This was mainly done by discussing the conceptual framework used, research design and the recruitment procedure. This chapter also discussed the ethical considerations undertaken throughout the research process as well as a discussion about the strengths and limitations of the study. My wish upon completion of this project is to not only produce a research that will benefit my professional career and personal development positively but also to bring about a positive outcome and initiate a positive change concerning the research participants and other persons with autism and their friends.

CHAPTER 4

FINDINGS

CHAPTER 4 : FINDINGS

Introduction

This chapter presents the findings of the interviews held with five individuals on the autism spectrum. In order to adhere to the principles of emancipatory research and give primacy to the voices of the participants, the findings are presented separately from the interpretations and discussion.

The table below provides a brief description of the participants so as to acquaint the reader with the participants' background. The chapter subsequently presents the findings, which were divided into themes and the topics covered included a description of the daily life activities enjoyed by the participants and their perception about the quality of their relationships. This chapter also covers the definitions and understanding given by the participants of their friendships. Past friendship experiences, preferred language as well as gender preferences are amongst the themes that also emerged from the participants' interviews. This chapter includes also the participants' self-perception when compared to others and ends with some observations by the participants about the future.

Table 1:

Name	**Age**	**Diagnosis**	**Interests**
Aria	19	Autism	Make up and sewing
Clayton	39	Autism	Computer games, TV series, History movies
Jon	25	Autism & Intellectual disability	Making new friends, traveling, Special Olympics, local band club, local feast
Nic	23	Autism	Computer games, play station games
Nora	20	Autism	Sports, reading, going out with friends

Daily life activities enjoyed by the participants

Recalling positive and difficult moments in their lives, the participants shared their experiences and daily routine as they lead life with autism. All participants involved in this research reside with their parents, apart from Clayton who is married and lives with his wife. Clayton and Nic are employed full-time, Jon works part-time whilst Nora and Aria are University students. In addition to her studies, Aria works part-time.

Maintaining repetitive and unchanged activities are amongst the difficulties associated with persons with autism as has been noted in the literature by Kanner (1943), referred to in Chapter 2. The responses of the participants were diverse and whilst it is a fact that all of the participants find themselves enjoying the same activities as they did when they were younger, all of the participants also mentioned initiating new interests in recent years.

Nic mentioned that, since the age of three, gaming was a very prominent part of his life. However, although gaming maintains its importance, he incorporates more important activities in his life nowadays.

> Nic: I've been playing games for twenty years so you can say I have plenty of experience. Gaming is still a big part of my life but not the biggest. Before I used to focus only on gaming but now I realize that with gaming only, my life will not be fulfilled. So nowadays I am going out more to enjoy what life has to offer.

Likewise, gaming is an activity enjoyed by Clayton since he was little. Clayton mentioned also that at a younger age, he used to enjoy spending time with friends during barbeques or other activities organised by the youth club he frequented. Clayton recalls several negative experiences with his friends at the time and thus he dislikes going out with friends nowadays. In fact, most of Clayton's preferred activities are solitary and home based.

> Clayton: I think I was more sociable when I was younger. With time I became less sociable ... and the group of people I trust is always getting smaller in size".

Like Clayton, Aria's preferred activities are ones that can be done alone. Aria has experienced rejections from friends in the past, experiences which continue to evoke sadness, as was evident during the interview. Aria mentioned being phased out by those she considered to be her best friends at the time.

> Aria: Whenever we would start arranging a meet-up, one would suggest we'd meet in Sliema for example and say I'm in, I'm in, I'm in and then I say I'm in

> and then a couple others who would have already said that they're in would say oh sorry I forgot I had something.

Despite her negative experiences, Aria mentioned two close friends with whom she enjoys spending her time. She also mentioned enjoying the company of her colleagues at work. Further to her interests and hobbies, Aria has recently started to sew and apply her own make-up. She also mentioned that at a younger age she didn't have as much time for hobbies due to her school commitments.

Jon expressed liking the exact same activities nowadays as he did when he was younger, activities which are mostly related to outings with his friends. Unlike the rest of the participants, Jon's friendship experiences were always very positive and in fact he recalled having a lot of friends. Whilst the activities that Jon enjoys revolve around his friendships, during the interview he expressed that he does need some alone time. Similarly, Nora talks about enjoying similar activities nowadays as she did when younger.

The participants' perception about the quality of their friendships

In their responses, all five participants attributed value to their friendships despite their previous negative experiences.

> Nora: I think it's sort of valuable to have people that you can call friends and who want to spend time with you sort of.

> Aria: [referring to friendships] makes me happy, really, having friends.

With the exception of Clayton, all participants could mention at least one good friend with whom they enjoy spending their time. Interestingly however, the majority of preferred activities mentioned by all the participants, excluding Jon, did not necessarily involve a partner. The fact that most of the activities mentioned could be carried out alone, raises questions on whether this is due to the participants enjoying some alone time or rather because they do not feel understood by their peers. Indeed, trust and loyalty were amongst the most valued qualities mentioned by the participants when asked for factors they consider to be important in the formation and maintenance of friendships.

> Aria: A person who I can trust and respect and it's mutual.

> Clayton: Loyalty and the fact that a person understands you. A person that understand that you cannot do certain things in any other way. A friend understands you.

Another possible reason participants may opt for hobbies that can be done alone is that they do not feel understood by their peers both emotionally and by the manner in which they express themselves.

> Nora: Sometimes for example I would have something that I would want to talk to them about and sort of they'd be tired of me talking about it.

Similarly, Nic and Aria mentioned experiencing difficulties when outings to discos, such as in Paceville, are planned. For this reason, the participants are excluded from group outings that can help friendships blossom. Nora said that her football team mates organise frequent outings, however since she declined to join some outings in the past, they no longer invite her. On a positive note, both Nora and Aria mentioned being frequently involved in decision making when planning group outings with their closest friends.

It is interesting to note how Aria, Nora and Nic mentioned their preference of not sharing personal life experiences with their colleagues despite having good relationships with them.

The participants' definition and understanding of friendship

The diversity in the responses of the participants, when they were asked to define a friend, reflects their different life experiences of friendship. Such experiences varied from positive to negative across the different periods in their lives. Interestingly, in addition to the typical definitions of friendships such as describing a friend as an individual who is kind, caring and respectful, answers given by the participants included characteristics such as tolerance, respect and abstaining from judgement.

> Aria: A friend is someone who can tolerate you, whatever quirks you have.

Such definitions reflect the participants' previous negative experiences and the manner in which they value and perceive themselves in relation to their peers. Aria mentioned her negative traits and longs for her friends to look beyond these traits such that friendship can flourish.

> Aria: I stammer a lot, I say things without thinking. A friend is someone who can tolerate those, accepts them even and be there for you when you are troubled and staff [pause] someone who won't judge. That is what a friend is to me.

Furthermore, she mentioned the importance of mutual commitment in order for the relationship to be successful. Similarly, Nora commented on the importance of shared interest to create and maintain successful friendships.

> Nora: Someone who have mutual interest to enjoy spending time with. Who is there if you need them.

All the participants excluding Jon, highlighted the importance of loyalty and trustworthiness. Furthermore, all five participants mentioned the importance of mutual commitment in a successful friendship.

> Clayton: Most of the friendships I had because they needed me.

Clayton recalled being used by his friends, because he was there when they were in need but this was not reciprocated. Along the same lines, Nic expressed feelings sadness when he attempted to build a relationship of trust and ultimately ended up disappointed with the outcome of a failed friendship. Both Nic and Clayton mentioned the fact that they are on the autism spectrum as a reason why some friends have terminated friendships in the past.

All participants emphasized the importance and value they attribute to their friendships and evidently such friendships hold a significance in their daily lives. Aria said that having friends makes her happy, however she admitted that she finds it difficult to maintain such friendships. She explained that this is mainly because she does not feel that her friends fully understand her. Aria explains that this is partly because of the language difficulties she encounters, as will be elaborated upon later in this chapter. To an significant degree, the value that the participants give to their friendships contradicts societal beliefs that persons with autism experience an innate desire to be alone. As a matter of fact, the participants' responses highlighted their desire to have friendships even when four out of the five participants reported having negative experiences in their friendships. Such experiences were also reflected by the manner in which the participants chose to define a friend. This was evident since in their responses additional value was placed to qualities such as trustworthiness, loyalty and the ability for one to be open and accept their flaws.

Clayton said that he had been more "sociable" at a younger age and that his circle of friends grew smaller and smaller such that at present he was unable to think of one good friend apart from his wife. Clayton expressed his disappointments when recalling past experiences in that those which he considered to be his friends were not there for him as he was when they needed him. Equally emotional were Nora’s recollections of feeling left out by those she considered friends, despite being present in their lives when they needed her. Notwithstanding her negative experiences with her previous friends, Nora mentioned two friends that she considers to be close and with whom she enjoys sharing her life.

The answers that the participants provided on their definitions of friendships brought to light their negative experiences as they lead their lives with autism as well as the fact that stereotypes upheld by society affect how they in turn view themselves in comparison to others. In this regard, Aria stated "A friend is someone who can tolerate you, whatever quirks you have." In her statement, Aria takes responsibility for her "negative" qualities and is grateful when her friends overlook such negative traits in her.

Friendship experiences from the participants' viewpoint

The participants had both positive and negative experiences to share about their friendships. Notably, however, all participants expressed that a lot of effort and work is required for the maintenance of such friendships. All participants mentioned the importance of having common likes and interests in order to maintain their friendships.

> Nora: To establish a friendship, you'd have to have something in common. Then someone has to initiate it and then to maintain it you have to sort of be ready to do things for the other person and listen to them.

The initiation of a new friendship is seen as challenging at first by the female participants. Nora mentioned that due to her social anxiety, someone else has to initiate the conversation. Similarly, Aria states that she is not usually one that initiates a conversation, however if someone else starts, she follows. Aria attributes her fear to initiate a conversation to her fears of rejection.

> Aria: I don't consider myself as a shy person. Not exactly. Um, I'm not, I guess that I fear if they don't like what I'm suggesting like if we're going to this place and they don't like [the place]?

Nora mentioned that the difficulty that she experiences to fully express herself with her peers continues even as the friendship grows.

> Nora: I think mostly unless it's something that is really bothering me, I don't express it. Usually it doesn't bother me sort of. It does not bother me emotionally, it just happens.

Nora mentions that she greatly values her friends and is grateful for their understanding and that this is the reason she is afraid to fully express her opinions especially when she is not in agreement with them. Furthermore, she states that her friends have a tendency to "get tired" of her talking about the same things and thus she tends to opt out of such conversations.

In contrast, Jon and Clayton mention having no difficulties with initiating a conversation however Clayton declares having higher levels of anxiety once a friendship starts to develop and become more serious. This is mainly due to his negative past experiences. Similarly, Aria recalls having no friends when she was younger, "Really at primary I was alone". She recalls her experience at school and spoke about the little support she received from her peers and teachers at the time.

> Aria: I hated them. I hated my teachers in primary. In fact in primary I remember when I was acting weird, or you know "autistic", they would say "Oh she's fine, she just lazy". The head mistress had a degree in educational psychology or something and child psychology and she didn't notice.

Correspondingly, Nic expressed having little support at school from his teachers especially due to language barriers as will be elaborated upon later in this chapter.

The participants' gender preference in friendships

The participants were asked whether they prefer female or male friends. Nic and Aria said that they do not have a preference and would love to be friends with both males and females. Nora said that at a younger age she didn't have a preference, however nowadays she prefers to have females friends as she feels more comfortable around females than she does around males. In spite of this Nora is still partial to initiating and maintaining a friendship with a male.

> Nora: If a male friend would have the qualities of a friend I wouldn't say no just because he is a male.

As opposed to Nora, Jon prefers female friends as he believes that a female is more understanding and sensitive to his experiences than a male. Interestingly however, given the chance Clayton would prefer to have a male friend as he believes that he would be less likely to be misinterpreted by a male. Clayton further elaborates that since his interests and hobbies are usually enjoyed by males, he would have more in common with a male than with a female friend. Having said this, Clayton reiterates that his only friend at present is his wife.

This topic provided the male participants, particularly Jon and Nic, with the opportunity to voice their wish to start a relationship with a female in hopes that one day they would be sufficiently committed to start their own family. Nic recalled a recent past experience with an ex-girlfriend and admitted he was still upset that the relationship ended.

> Nic: I have this ring, it gives me a connection. When I look down I feel like it's there and I still keep it close to my heart and in the future [pause] I'll keep it and it feels like a memento.

Notably, all the participants mentioned being open to new friendships with either gender as long as the other individual is nice to them.

> Aria: I honestly don't care. I mean if they are nice to me then I'm nice to them, that's it.

Preferred language by the participants

In light of the fact that Malta is a bilingual country, the participants were asked whether language had ever been an issue. Aria expresses having encountered difficulties when younger since all her peers were Maltese speaking and she stood alone because she could communicate better in English.

> Aria: It's awkward when in a group everyone is speaking in Maltese and I'm the only one speaking in English.

This used to make Aria feel left out of conversations and ultimately not valued at the same level as other group member. Similar to Aria's experience of not being included in the group due to the fact that she was English-speaking, Nic recalls friendships ending due to the fact that he spoke "differently" than the rest.

> Nic: Honestly, they didn't accept me much because I am autistic. They used to think I'm a freak back in the past and even nowadays sometimes because of the way I speak. They viewed me differently because of my accent.

In contrast, the experience of the other three participants was not so negative. Apart from Jon, all participants expressed preferring English over Maltese. Interestingly however, both Clayton and Nic wanted to do the interview in Maltese even if they are more fluent in English.

Jon is Maltese speaking and his understanding of the English language is limited. However, he declared that this fact does not limit his communication with English speaking individuals.

> Jon: For me, it doesn't make a difference if the person is black, American, Chinese, Brazilian, or Colombian .... It doesn't make a difference for me, a friend does not have to be Maltese.

Nora mentioned associating certain people with a specific language however, like Jon, she does not recall any particular difficulties with regards to language.

Feeling less worthy than others

As has been seen through their responses, the participants acknowledged a deficit in them due to their autism diagnosis. This was evident in all of the participants' responses.

> Aria: I stammer a lot, I say things without thinking.

> Nic: I am very naive and people use me to their advantage... I am shy. Most often uncomfortable. This is extremely common for people like me [autistic].

Jon mentioned that due to his disability he does not involve himself in certain hobbies and asserted that once he is "cured" from his disability he will practice further interests that he would be in a position to do on his own.

> Once I am cured from my disability, I would be able to go abroad on my own.

Clayton verbalized his thoughts of feeling less worthy than others and expressed his tendency to blame himself for not being at par with others, particularly his brother, whose qualities were different to his.

> Clayton: I had typical symptoms of autism; speech delay, speech problem impediment ... my speech was not normal. My brother was always very sociable and athletic and I ... [pause] was not. There was a lot of ... [pause] what's wrong with him [referring to himself]. I dislike big groups of people, I am rigid... [.]

Autistic but not aggressive

A prevalent assurance of not being dangerous and aggressive was given by all three male participants. Nic, Clayton and Jon mentioned that despite feeling angry about certain issues they know how to control themselves and as such are not dangerous. Nic mentioned that certain things make him so angry that he feels compelled to assure others that he is able to control his "rage" and is therefore of no danger.

> Nic: I don't have anger issues, I have a rage but I can control it but when people try to do everything that they can to leash my full anger, I say stop you don't want to see me like this and they want to push..[.]

Clayton spoke about his rigidness, about following the rules and the difficulties he experiences when others do not give the same importance to these rules. Despite this, Clayton mentioned that he is in control of his anger and thus, like the other male participants, assured me that he is not dangerous. Similarly, Jon mentioned the importance of not being aggressive and spoke about the advice that he gives to his friend, who he describes as violent and sometimes, also aggressive.

> Jon: I do not wish for him to be aggressive towards nobody.. [pause] I scare him and tell him not to be aggressive because he will end up in jail. I tell him that I will not go and see him!

Moving on from the autism diagnosis into the future

It is interesting to note how despite not being asked directly about their romantic relationships, all three male participants mentioned their plans for the future. As previously mentioned, one of the male participants is married and expecting his first born. The other two male participants mentioned that they wish to initiate and maintain a romantic relationship.

> Jon: One day, I wish to get married.

Nic mentioned his temptation to not "be himself" so as not to scare away a girl who is romantically interested in him. Having said this, Nic mentioned that this has triggered negative feelings towards himself in the past.

> Nic: I try to be not myself, sometimes I try to not be me but then I would become an even more idiot [sic], sometimes I try something new and it fails, everything seems to always backfires and I haven't to this day met one that cared so much about me.

Nic recalled a past romantic experience with a girl who is also on the autism spectrum and expressed that even though they are no longer romantically involved, he continues to care for her.

> Nic: I still love her even though I know I shouldn't, I am still moving on. Actually I have this ring, she gave it to me on Valentines' Day, I wear it occasionally, sometimes I feel like doing so, I feel when I wear the ring, it gives me a connection. When I look down I feel like it's there and I still keep it close to my heart and in the future [pause] I will keep this ring as a memento.

Clayton expressed feeling understood and supported by his wife and mentioned feeling grateful towards her as she understands his difficulties.

> Clayton: My wife, is my only best friend. She is my friend, she understands me, is patient with me even when I occasionally lose control.

Interestingly, none of the female participants mentioned anything related to their relationships with males.

Conclusion

This chapter presented the findings that emerged from the interviews held with five individuals on the autism spectrum. Their responses reflect the manner in which the participants understand and make sense of their past and present experiences of friendships. The participants' responses highlight the fact that despite being aware of their right to be treated as others, their self-perception is negative on account of how they are regarded and treated by society in general. The findings also highlighted the fact that the participants enjoy the company of others however they have acquired a learnt behaviour to safe-guard themselves from future hard-ships. The next chapter will discuss the findings, guided by literature and my own personal interpretations through the interpretative phenomenological approach.

CHAPTER 5

INTERPRETATIONS AND DISCUSSION

Chapter 5 : Interpretations and Discussion

Introduction

The purpose of this study is to obtain a better understanding of the meaning that persons with autism attribute to their past and present experiences of friendships. In order for this to be achieved, this chapter presents a discussion of the themes that emerged from the participants' responses. This analysis provides evidence that challenges received ideas about people with autism and their relationships with others. In fact, the predominant finding of this analysis are the contradictions that emerged from the responses of the participants and the assumptions about persons with autism. These contradictions and contrasts shape the results of this analysis and it is for this reason that the themes incorporate two outcomes. This discussion is guided by literature, followed by my reflections and interpretations of the participants' responses to the research questions.

Concepts

The phenomenological concepts discussed in more detail in Chapter 3 will be applied to the themes that emerged from this analysis. During this discussion reference is made to Heidegger's concept of Dasein, Mitsein and Throwness in relation to the experiences of persons with autism and their friendships. As already noted, Dasein refers to the being-in-the-world of an individual and for the purpose of this study Dasein will be used to refer to the individuals with autism. On the other hand, Mitsein refers to the being-with-others which, for the purposes of this dissertation, refers to the friends of the aforementioned individuals. Humans are not meant to live isolated from other human beings and as such they tend to develop not only an understanding of their "self" but also an understanding of 'others' (Moran, 2000). Dasein and Mitsein are "thrown" in a society, with its pre-established norms at a particular point in time and space which in turn impacts their being-in-the-world. Thus the way that the persons with autism interact with others is influenced by their autism diagnosis as society ascribes their being to the characteristics of having autism. Therefore the experiences of the research participants living in Malta in the 21st century differ from the experiences of other human beings with autism living elsewhere in the world and in other time periods.

For this reason, despite the emergence of the social model of disability (UPIAS, 1976), inclusive education (UNESCO, 1994), the Equal Opportunities Act in 2000 and better service provision (Formosa, 2009; Vella, 2017), the participants' experience in Malta in the 21st century is still problematic. In their responses the participants exhibited an awareness of their rights but since society continues to cast them aside on the basis of their autism characteristics, they are forced to feel and be treated as less than the rest of society. Hence, whilst society categorises the being of the individuals with autism as different and therefore deviant on account of their autism, the individuals with autism in this study exhibited an awareness of the manner by which they are treated in society. It is for this reason that the life-world of the individuals with autism continues to be afflicted by the negative stereotypes and stigma that are imposed on their being in society on account of their autism diagnosis. At the same time, ironically, the blame that is experienced by the individuals is ascribed to their autism characteristics and as a result the individuals with autism are forced to withdraw into a more solitary way of being-in-the-world because of the socially constructed barriers they encounter. This contrasting situation has lent itself to the identification of themes that reflect the paradoxical relationships that persons with autism have with others.

In this study, five persons with autism shared their experiences of friendships and through the interviews, they disclosed their understanding of their being-in-the-world in relation to their understanding of being-with-others. The table below give an overview of the themes that emerged from the interviews with the participants:

Table 2:

Main Themes	**Sub Themes**
Being with others or being alone?	Being alone or being lonely?
How the participants view themselves or how others view them?	Valued members or insignificant others?
	Sick and deficient?
	Friends or friendly?
The social and medical model co-existing	
Reciprocity of support	
Gender differences	

Being with others or being alone?

As noted in the literature review, according to Kanner (1943) children with autism are believed to be born with an inability to form successful bonds with others due to their innate desire to be alone. Similar research to that of Kanner was published by Hans Asperger in 1944. Like Kanner, Asperger noted a deficit in the participants’ social and emotional functioning despite good cognitive ability (Deisinger, 2015). Other research studies, such as those by Bauminger and Kasari (2000) and Petrina et al. (2016), assert that the difficulties that the individuals with autism experience in their friendships develop following an innate deficit from the individual to initiate and maintain successful friendships. Contradicting these assertions are the findings by Potter (2015) and Vine-Foggo and Webster (2017) that affirm that the participants enjoy and appreciate the company of their friends. Despite the fact that similar findings emerged from the interviews with the participants in this study, their responses confirmed that the answer to the question on whether persons with autism prefer being with others as opposed to being alone is complex for the multiple reasons that will be discussed in this analysis.

The main points that will be discussed in this chapter include a discussion on whether loneliness is a choice, how the participants view themselves on account of how they are perceived in society and the participants' account of their value within their peer group. This analysis will also discuss the participants’ understanding of what being a friend entails from the participants' viewpoint.

Being alone or being lonely?

When asked about their past and present experiences of friendships, all of the participants spoke about the importance and value they attribute to their friendships. Additionally, all participants mentioned being content and satisfied when their friends reciprocate the friendship. However, when the participants were asked to mention their hobbies and preferred interests, oddly enough, most of the hobbies mentioned could be carried out solitarilty, without the need of another party’s participation. Whilst there is no definite answer to explain this reasoning, the participants' responses indicate that one possible reason could be their negative experiences of past friendships. It is therefore possible that participants learn this behaviour as a means to safe-guard themselves from further let downs rather than choosing solitary activities because they would prefer to stay in isolation from others. This solitary way of being allows the individual a sense of control in order not to experience further negative emotions and by protecting the self from additional disappointments. This was expressed by Clayton when he said he was more sociable when he was younger, adding that at present he was not able to identify one single true friend. This assertion is in discordance with the majority of the literature on the topic as the aloneness that surrounds persons with autism is attributed to their autism characteristics as previously mentioned.

As can be noted by the research findings of Bauminger and Kasari (2000), and Bauminger et al. (2003), the being-in-the-world of persons with autism is highly infused by pre-dominant ideology that their autism label automatically equates to an innate deficiency to successfully initiate and maintain friendships. However, when taking into account the lived experiences and understanding from the standpoint of the individual with autism, one can easily note that the preference for aloneness originates following several attempts by the individual with autism to initiate and maintain successful friendships. This reasoning identifies with the fundamental principles of the social model of disability, whereby the difficulties that the individual with autism experiences are attributed to the lack of support given by society, more specifically, in this study, by the friends of the individuals with autism. Therefore, this study notes how individuals with autism are somehow trapped within a cycle of being prescribed a priori the loner title when, in actual fact, their behaviour is a direct reaction to the manner in which they are treated by others. Nevertheless, despite previous negative experiences of friends, all participants, apart from Clayton, mentioned at least one good friend with whom they share their life experiences. Furthermore, the importance of sharing their life with others was clearly identified in this study as even Clayton spoke about the experiences he shares with his wife, whom he considers to be his closest and most valued friend.

The participants' responses verify that they understand their Dasein as also comprising Mitsein, however are forced to disengage into a more solitary way of experience on account of the societal barriers encountered in their everyday living.

How the participants view themselves or how others view them?

As previously mentioned, Heidegger's concept of Dasein is strongly intertwined with that of Mitsein. In other words, the being of the individual is always relative to the experiences of being-with-others. Consequently, apart from trying to be aware and understand their own selves, humans attempt to understand others. It is for this reason that the manner by which human beings understand their selves is influenced by how others relate to them. Therefore it is impossible for individuals to live their experiences in a vacuum away from others as the world is already "humanised" (Moran, 2000, p. 242).

The influence of Mitsein on Dasein was also evident by the way that the participants responded to the questions asked. The participants' responses indicate that their self-image is influenced by how society perceives them. The participants' awareness of their being in society in relation to others could also be noted in the words they chose to describe their characters, likes and dislike. It is therefore not surprising that the participants described themselves in a negative manner as evidenced by their "quirks" in character described by Aria. It is equally significant to note the forceful impact that society has on individuals with autism as they are considered to be loners on account of their deficits when in reality their being is predominated by society's understanding of their autism diagnosis. The participants' responses reflect how persons with autism internalise the way they are perceived by society and in effect their understanding of their selves would reflect society's perception and ideologies.

This line of thinking coincides with Heidegger's concept that humans are "thrown" in a world that is already interpreted and constructed. Society categorises the actions of individuals with autism by how the characteristics of autism are understood and construed in society.

Furthermore, since the world is already interpreted, certain characteristics in the individual are positively perceived whilst others are frowned upon. Clayton mentioned his internal conflict of not being able to conform with the expectations that society has of him especially when his self, more specifically his being is compared with that of his brother, whom he described as being sociable, athletic and non-rigid.

Valued members or insignificant others?

As previously discussed, the life-world of persons with autism is influenced by their diagnosis vis-a-vis their relationship with others. Individuals with autism are "thrown" in a society with fixed ideologies about the diagnosis and as such when their being does not comply with the standards dictated by society, they are forced to withdraw their full participation. The renunciation of persons with autism from being fully involved in society is then justified as a characteristic of autism and the deficits thereof. The shared experiences of the participants highlighted the feelings they experience when they do not believe themselves to be an integral part of the group and thus less valued members of their circle of friends. In their responses, the participants mentioned that such feelings lead them to withdrawal from fully expressing themselves with the rest of their peers and ultimately find themselves excluded from their circle.

In his book *Being and Time*, Heidegger (cited in Moran, 2000) talks about the fact that human beings acquire an understanding of themselves unconsciously. However, this understanding is adopted by the manner in which "life presents itself" (Moran, 2000, p. 239). In other words, the way that an individual is presented and regarded in society affects how that individual will perceive and understand his/herself. Hence, as previously mentioned, the fact that the individuals with autism perceive themselves through the eyes of others diminishes their worth as valued members of the group and, as a consequene, they refrain from expressing their opinions and suggestions. In fact, the reluctance of sharing their opinion and the unwillingness to confront their peers was noted in the responses of all the participants in this study. As noted in the literature review, friendship dissatisfaction was evident in several studies with children, adolescents and adults with autism (Calder, Hill and Pellicano, 2013 & O'Hagan and Hebron, 2017) and the reason for this can be attributed to the fact that such individuals feel less worthy when compared with their neuro-typical counterparts. The assertion that the difficulties experienced by persons with autism results from the fact that they feel less worthy than their peers is in discordance with the literature as the dissatisfaction that the individual with autism experiences is believed to be a direct result of the autism diagnosis and the innate inability for successful relationships.

As has already been noted, the participants mentioned a discontentment at some point in their lives with their ascribed value within their circle of friends. Another related issue that emerged from the interviews with the participants about their lived experiences is that of "being used" only when needed. In keeping with the feelings of worthlessness, the participants mentioned feeling betrayed by those they considered to be close to them.

Sick and deficient?

As previously noted, the perception that the participants hold about themselves on account of how others perceive them in society is a negative one primarily because the individual is perceived solely on the characteristics that make him or her "autistic". The belief of being sick and deficient on account of their autism diagnosis brings about another contradiction in that they want to be accepted as they are and yet perceive themselves as having deficits.

As has been seen above, the participants' responses indicated an acknowledgment of their limitations and attribute such difficulties to their autism diagnosis. This perspective was made even more evident when Jon mentioned that one day he will be cured from his disability. This view reinforces the belief of disability as a sickness that needs to be cured, a belief held not only by society but even by the individual with disability himself. This is a view that is consistent with the concept of Dasein and Mitsein and the influence of the being-with onto the being, as discussed in more detail earlier on in this chapter.

Friends or friendly?

The participants' understanding of their friendships was highlighted also by the choice of qualities a friend must possess in order to be deemed a good one. More specifically, in their responses the participants accorded heightened value to qualities such as that of trustworthiness, loyalty, patience and understanding. Furthermore, they spoke about the importance that a friend accepts and tolerates them. All things considered, the fact that the participants spoke about the importance of being tolerated by others continues to reinforce the fact that they perceive themselves in a negative light, based on the assumptions of others as has been argued in more detail earlier on in this chapter. The nature of Dasein changes because of its link with that of Mitsein. Therefore the lived experiences of the individuals with autism changes according to the way they are with others and more importantly the way that others are with them.

Interestingly, while a general consensus came to light in the responses of the participants in the form of an unease in fully expressing themselves in front of their friends due to their fear of rejection, Nic and Jon mentioned being more comfortable in the company of another friend with autism. Nic spoke about an immediate bond with his friend with autism because he is like him and hence he is not alien to the experiences of friendships given the fact that he too leads a life with autism. It is equally interesting to note that Mitsein, which in this case refers to being with another individual with autism, influences the Dasein and the shared lived experiences.

As previously mentioned in their responses the participants identified important characteristics that a friend would have to possess. Nonetheless a difference in the participants' responses was noted and, whilst the research participants in this study that have autism as their sole diagnosis proved to have a good awareness of the state of mind and intentions of others as well as empathy awareness, Jon, who has an intellectual disability in addition to autism, exhibited a higher tendency to perceive friendly acts as friendships.

The social and medical model co-existing

One of the main themes that come out in this analysis was the paradoxes that influence the lived experiences of the individuals with autism. In effect, the life-world of the individuals with autism is inspired by both social and medical model thinking. Indeed, even as the participants in this research exhibited an awareness of their rights, their responses addressed their withdrawal from fully acquiring these same rights which include being treated as equals in comparison to other neuro-typical individuals.

Thus whilst the participants are conscious of their rights of being equal to other individuals in society, nevertheless their responses indicated their acceptance of being treated as less and inferior to others in society. Consequently in addition to feeling less worthy on account of how they are perceived in society, in their responses the participants accentuate an acceptance of unequal relationships as long as they experience friendly relationships.

Having looked at the contradictory issues that emerged from the participants' interviews there were themes that emerged and are equally important but not of a contradictory nature.

Reciprocity of support

As previously mentioned, in their responses the participants placed value on the support given to them by their friends. Nevertheless, they declared that they attribute equal importance to the support they must give to their peers. The awareness that the research participants possess about the importance of reciprocity of support in friendships is consistent with the research findings of Vine Fogga and Webster (2017). In their study involving adolescent girls with autism aged between thirteen to seventeen years, Vine Fogga and Webster found that the girls correctly identified the characteristics needed to maintain a friendship with a best friend and this included the reciprocal input that is needed from both parties. It is therefore ironic that, whilst an explicit effort is being made by the participants to be good and valued friends, nonetheless they feel less worthy than their counterparts as they still feel they need to be tolerated for their negative, autism related qualities.

Furthermore, although the participants spoke about how they value and derive satisfaction from their friendships, they also spoke about the difficulties they experience to initiate and maintain friendships, particularly within a group setting. This was especially evident in the responses of the female participants, an issue that is returned to later on in this chapter, as they expressed uncomfortable feelings when in need to initiate a conversation with the aim of starting a new friendship. Nora, who experiences social anxiety, acknowledged this discomfort to be of hindrance in the initiation and maintenance of friendships even though she would then be willing to participate in the groups' plans and activities, once included.

Trust, or the lack of it, was another important factor that was noted to cause difficulty to the participants as past negative experiences continue to have a hold on the participants despite their explicit wish for meaningful friendships. With this process the individual experiences an internal conflict to try and overcome the limitations of their diagnosis, those characteristics that society labels as deviant, and in the face of failure, the individual is bound to experience self-stigma. Thus, as previously noted, the influence of the Mitsein onto the Dasein is significant as the attitudes of the individuals in society hold significance to the being-of the individual with autism.

Gender differences

When asked about their gender preference, four out of the five participants chose a female friend as they believe that females have a higher tendency to understand and be sensitive to their feelings. Clayton was the only participant who mentioned that, given the choice, he would prefer having a male friend as this would decrease the risk of him being misinterpreted or even misunderstood. Interestingly however, as pointed out in the previous chapter, he also mentioned that his current friend is his wife, by whom he feels understood and hence does not have any particular fear of being misinterpreted given they have established a secure relationship of reliance and trust. Despite expressing their gender preference, all the participants highlighted the fact that they are more willing to initiate and maintain a frienship on the basis of other desired qualities than simply on gender.

A prevalent issue that was spoken about by all three male participants was that of romantic relationships. In their responses Jon and Nic expressed their desire to have an intimate relationship whilst Clayton spoke about his family and future plans. On the contrary, none of the female participants spoke about their future plans and desires and whilst this could be because they were not explicitly asked to do so, it could also be due to their self perception as having deficiencies and thus not worthy of having a romantic relationship and eventually their own family.

Furthermore, it is also interesting to note the manner in which the male participants chose to re-assure me, as a female individual, that they are not aggressive. This response further confirms that the male participants in this study have internalised a sense of being ‘less than’ and being in the wrong so much so that they felt it imperative to make it clear they are not aggressive despite being "autistic". The assertion that individuals with autism are more aggressive when compared to other neuro-typical individuals is supported by the research of Fitzpatrick et al. (2016) and Bronsard, Botbol and Tordjaman (2010). This further affirms the nature by which Mitsein affects the being of the self as the participants’ perception of themselves is directly influenced by the stereotypes of society.

Conclusion: living with paradox

This chapter presented a discussion of the themes that emerged from the interviews held with five participants on the autism spectrum. As has been noted in this chapter, the being of persons with autism is highly influenced by the manner in which society understands and classifies the autism diagnosis. The label that such individuals are given by society is reflected by the way that the participants described themselves and their experiences.

This chapter made reference to Heidegger's concepts of Dasein, Mitsein and Throwness to further understand the being of the individuals with autism in relation to others. Equally important is the consideration of the being in space and time and thus the lived experiences of five Maltese individuals, living in Malta in the 21st century.

This chapter highlighted also the paradoxes that surround the lived experiences of persons with autism and, despite being qualified as deviant on account of the diagnosis, the participants' responses reflected not only an understanding of their being in society but also their being with others that very often predominates their lived experiences and overall life satisfaction.

The next chapter presents a summary of the main findings together with the strengths and limitations of this research study. Future recommendations and my own personal reflections of this journey will be presented in this concluding chapter.

CHAPTER 6

CONCLUSION

CHAPTER 6 : CONCLUSION

Introduction

This chapter presents an overview of the key findings related to the research questions below:

> How are past and present experiences of friendships perceived by persons with autism?
>
> How do young adults with autism describe their past and present experiences of friendships?
>
> What factors contribute or hinder the relationships of young adults with autism and their friends?

This chapter also covers the strengths and limitations of this research as well as recommendations for future studies. The final section presents some personal reflections of this learning research journey.

Key findings

This study explored the lived experiences of friendships of five adults with autism. The participants were provided with an opportunity to voice their experience and a chance to speak about the way they understand their experience, given that they are the experts of their lives. Through one-to-one semi-structured interviews, the participants provided insights into the manner by which they understand and interpret their past and present experiences of friendships.

One of the key findings of this study is the participants' desire for friendships and their understanding of what constitutes a friendship. The participants' responses showed that even though they have negative experiences of friendships, they still value and enjoy the company of others. These findings are in discordance with the literature that stresses that difficulties that individuals with autism experience are attributed to the deficits of the individuals which are believed to be directly derivative of the autism diagnosis..

Reference to Heidegger's concepts of Dasein, Mitsein and throwness were made to further understand the being of the individuals with autism and their friendship relationships with others. In this study, Dasein referred to the being-in-the-world of the individuals with autism whilst Mitsein was used to refer to the being-with friends of these individuals. Another key finding that emerged clearly from this research was the impact that Mitsein has on Dasein, that is, the influence that the friends of persons with autism have on their identity and self-perception. All of the participants have a key role in society, whether that of a husband, daughter, son, student or employee. However, their identity and self-perception are highly influenced by how others view them. This was evident by the manner in which the participants described themselves. The description about their selves – highlighting mainly their difficulties – reflected the participants' understanding of how others view them. The participants' understanding of their selves as less worthy than their neuro-typical friends was reflected also in the way they spoke about their tendency of not giving their opinion especially in confrontational situations.

The participants' own characteristics and personal experiences provided the study with five unique stories about their lived experiences with their friends. The participants expressed the desire to share their experiences in order for them to be better understood and be seen first and foremost as persons before their diagnosis. In fact, regardless of the uniqueness of each of the participants, there were commonalities amongst the experiences due to their similar diagnosis.

Furthermore, this study acknowledges that despite the fact that all the participants had negative experiences of friendships, each could still identify a close person with whom they share intimate secrets and enjoy spending time with. Notwithstanding this, the hobbies enjoyed by all of the participants could be done alone. This study concludes that this behaviour is a learnt behaviour in order for the participants to safe-guard themselves from further disappointments.

In almost every aspect, the element of paradox was evident in the experiences of the participants. These contradictions form the foundations of the main findings of this research as, in spite of the participants' desire to be accepted and be treated as equal members in society, society continues to cast them aside on the basis of their diagnosis. The participants' longing to be accepted was evident in their responses and yet they perceived themselves as having deficits and, for this reason, accept to be treated as less as long as they have friendly encounters.

Strengths and limitations

The use of phenomenology with guidance from the principles of emancipatory research was a valuable means to better understand the lived experience of the participants. The use of the social model of disability strengthened the focus that the difficulties experienced by the participants to successfully initiate and maintain their friendships were a result of the barriers created by society.

This study also provided the participants with a chance to share their lived experiences and an opportunity to make their voices heard. This research proposed a shift in thinking that the difficulties related to friendships that are experienced by the individuals with autism are derived following their limitations and instead the focus was set on the limitations and barriers that society inflicts on these individuals.

Through the use of IPA, the findings of this research are inevitably influenced by double hermeneutics as my own interpretations of the participants' responses shape my own way of being. Thus, my interpretation of the findings is influenced by my position as a non-disabled researcher, with a professional and personal relationship with several children and adults with autism.

Since this study adopted a qualitative approach, a small and homogenous group was chosen and thus the findings of this study cannot be generalised. However this was not the intention of the study. My focus was to acquire rich and detailed accounts of the participants' lived experiences and thus acquire a comprehensive view of the participants' realities.

Recommendations

Following the findings of this study a number of recommendations are hereby proposed. As stated in Chapter 1, this research knows its origins from the pre-occupations of a mother of a teenage girl with autism following a number of difficulties that her daughter was experiencing to initiate and maintain successful friendships. Thus this study recommends the importance for educators to encourage the inclusion of children with autism within the classroom from an early age.

This study recognises the importance for all individuals to be treated equally whilst acknowledging the importance that each individual is valued as such rather than being seen as another individual with homogenous needs to other individuals with autism.

An opportunity was provided to five individuals with autism to speak about their experiences and their interpretation of their own experiences was discussed in detail throughout this dissertation. This study proposes more peer-led support groups, with input from professionals where required, in order to facilitate an environment where individuals with autism can share their point of view and the manner by which they experience their friendships.

While this study acknowledges the limitations that the media can have on the presentation of persons with autism, it can also be used for individuals with autism themselves to speak about their experiences. Talk shows and discussion programmes could provide individuals with autism the exposure needed to improve awareness and, in so doing, deconstruct persistent stereotypical beliefs of persons with autism as loners by choice. Furthermore, the use of media can potentially help the active participation of individuals with autism in society.

Further research is also needed to explore the lived experiences of friendships of non-verbal individuals with autism. Future research could also explore the interpretations that neuro-typical individuals have of their friendships with their peers with autism. This topic, although being important to the overall well-being of the individuals with autism, is under-researched to date, especially within the local setting.

Conclusion : Personal reflections and expectations

Whilst carrying out this research, I have encountered limited local studies that focused on the friendships of persons with autism. This research study was committed to explore the lived experiences and perceptions of the participants in the hope of promoting silenced voices in our society.

This study has left a considerable effect on me and has given me the opportunity to relate to several other individuals with autism I am in contact with on a daily basis. It has provided me with the opportunity to pause, listen to and understand the life experiences of a group of people that are most often expected to comply with the a priori status that derives of their diagnosis.

Now that this research has reached its completion, my hope is that the reader will achieve a better understanding of the lived experiences of persons with autism, in relation to friendship. I hope that through the findings of this dissertation a positive effect ensues in the lives of persons with autism whensociety acknowledges its disabling contribution to the difficulties experienced, even if this scenario will take time to be achieved.

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APPENDICES

Appendix 1 - Information letter to participants (English version)

Ms Antonella Micallef

Mobile number

e-mail address

Dear potential participant,

I am a second year student reading a Masters in Disability Studies at the University of Malta. I am writing in request of your approval to participate in a research study which will be carried out between 2018/2019.I have chosen to conduct this research following my interest to study, in depth, the significance that adults with autism attribute to the relationships formed with their peers. Thus, the main aim of this study is to explore the significance that young adults with autism attribute to their friendships.

The study will involve the participation of six young adults with autism, males and females, aged between eighteen to thirty-five years. Should you be interested to participate in this study, you are invited to contact me on my mobile or email address. You will then be invited to participate in a one-to-one interview. You are encouraged to make use of additional material such as photographs that will facilitate your arguments during the interview. In addition, you will also be invited to assist me in the formation of a booklet containing the responses of the interview. Your participation in the formation of the booklet is voluntary and you can still participate in the research should you not wish to aid in the formation of the booklet. The date and place for the interview will be chosen in accordance of your preference. Your participation will remain confidential and any potentially identifiable details will be removed. The interview will be recorded and transcribed. All information will be stored in a password protected computer. The information provided will be used for dissertation purpose only and will be destroyed after the completion of data collection. It is worth noting that your participation is on a voluntarily basis and you are free to withdraw from the study at any given time and without providing a reason.

Should you need any further information, please do not hesitate to contact me.

Thank you for your time and kind assistance,

I look forward to hearing from you,

Kindest regards,

Antonella Micallef

Appendix 2 - Information letter to participants (Maltese version)

Ms Antonella Micallef

Numru tal-mowbajl

Indirizz elettroniku

Għażiż parteċipant,

Jiena studenta tat-tieni sena f'kors ta' Masters fid-diżabilità ġewwa l-Università ta' Malta. Qed nikteb sabiex nistaqsi l-approvazzjoni tiegħek sabiex tieħu sehem fir-riċerka tiegħi li ser issir bejn l-2018/2019.

Għażilt li nwettaq din ir-riċerka għaliex għandi interess li nistudja fid-dettal is-siniffikat li żgħażagħ bl-awtiżmu jagħtu lill-ħbiberiji tagħhom. Għaldaqstant, l-għan ewlieni ta' din ir-riċerka huwa li nesplora s-sinifikkat li dawn iz-zgħażagħ jagħtu lir-relazzjonijiet tagħhom ma' sħabhom. Dan il-prinċipju huwa wieħed fundamentali għar-riċerka għaliex ħafna drabi dawn il-persuni ma jiġux mistoqsija għall-opinjonijiet tagħhom minkejja li jiġu studjati. L-istudju għandu l-għan li jippromwovi l-għoti tas-setgħa lill-parteċipanti filwaqt li jagħtihom l-opportunità li jesprimu lilhom infushom.

F'dan l-istudju neħtieġ il-parteċipazzjoni ta' sitt żgħażagħ b'awtiżmu, irġiel jew nisa, bejn it-tmintax u l-ħamsa u tlettin sena. Jekk inti interessat li tipparteċipa, inħeġġek sabiex tikkuntatjani fuq il-mowbajl jew l-indirizz eletroniku. Inti ser tkun mistieden biex tipparteċipa f'intervista miegħi. Inti mħeġġeġ tuża materjal addizzjonali bħal ritratti li jiffaċilitaw l-argumenti tiegħek waqt l-intervista. Kif ukoll, inti ser tkun mistieden biex tgħini fil-formazzjoni ta' ktejjeb li jkun fih ir-reazzjonijiet ta' l-intervisti. Il-parteċipazzjoni tiegħek fil-formazzjoni tal-ktejjeb hija volontarja u xorta tista' tipparteċipa fir-riċerka jekk ma tixtieqx tgħin fil-formazzjoni tal-ktejjeb.

Id-data u l-post għall-intervista jiġu magħżula skont il-preferenza tiegħek. Il-parteċipazzjoni tiegħek tibqa' kunfidenzjali u kwalunkwe dettalji li jistgħu jiġu identifikati se jitneħħew. L-intervista ser tiġi rrekkordjata u transkritta. L-informazzjoni kollha se tinżamm f'kompjuter protett minn password. L-informazzjoni provduta se tintuża biss għall-għan tad-dissertazzjoni u se tinqered wara t-tlestija tar-riċerka. Ta' min jinnota li l-parteċipazzjoni tiegħek hija fuq bażi volontarja u inti liberu li tirtira mill-istudju fi kwalunkwe ħin partikolari u mingħajr ma tipprovdi raġuni.

Jekk teħtieġ aktar informazzjoni, jekk jogħġbok, toqgħodx lura milli tikkuntattjani.

Grazzi għall-ħin u l-assistenza tiegħek,

Nistenna minghandek,

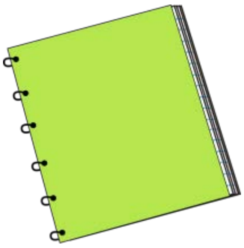
Tislijiet,

Antonella Micallef

Appendix 3 - Information letter to participants (English version - Easy to read)

Dear ______________________,

University of Malta	My name is Antonella Micallef and I am studying about disability at the University of Malta.
	As part of my course, I need to do a research project.
	I would like to learn more about the experience of young adults with autism and their friends.
	If you are a man or a woman with autism, aged between 18 - 35 years, I would like to meet you so you can share with me your experience about friendship.

	If you are interested to take part in this study please contact me on [mobile number] or e-mail address.
	If you are interested to take part in this study you will be invited to chat with me about your friends. You are encouraged to bring photos of your friends to help you while you explain.
	You are also invited to help me write a booklet with the information I gather from my chats. But you only need to take part if you want to.
	I would like to record our chat so I can take notes for my research. I will write notes about what you say but I will not write your name.
	I will delete all information after I am ready from my study.
	You will decide the place and date of our meeting.

	If at some point you do not want to continue taking part in the research you can do so at any time.
	Let me know if you need more information.

I look forward to hearing from you,

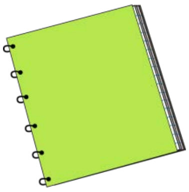
Kindest regards,

Antonella Micallef

Appendix 4 - Information letter to participants (Maltese version - Easy to read)

Għażiż/a ______________________,

University of Malta	Jisimni Antonella Micallef u qed nistudja dwar id-diżabilità fl-Università ta'Malta.
	Bħala parti mill-kors tiegħi, għandi bżonn nagħmel proġett ta' riċerka.
	Nixtieq nitgħallem aktar dwar l-esperjenza ta' żgħażagħ bl-awtiżmu u l-ħbieb tagħhom.
	Jekk int raġel jew mara bl-awtiżmu, għandek bejn 18-35 sena, nixtieq niltaqa'miegħek sabiex tkun tista' taqsam miegħi l-esperjenza tiegħek dwar il-ħbiberiji tiegħek.

	Jekk inti interessat li tieħu sehem f'dan l-istudju jekk jogħġbok ikkuntattjani fuq [numru tal-mowbajl] jew fuq [indirizz elettroniku]
	Jekk inti interessat/a li tieħu sehem f'dan l-istudju nistiednek biex titkellem miegħi dwar il-ħbieb tiegħek. Nħeġġek biex iġġib miegħek ritratti tal-ħbieb tiegħek biex jgħinuk waqt li qed tispjega.
	Int mistieden ukoll biex tgħinni nikteb ktejjeb bl-informazzjoni li niġbor fl-intervisti. Ħu sehem biss jekk tixtieq li tagħmel dan.
	Din l-intervista ser tiġi rrekkordjata. Waqt li titkellem jien ser inkun qed nieħu n-noti għar-riċerka iżda mhux se nikteb ismek.
	L-informazzjoni kollha ser titħassar wara li llesti mill-istudju tiegħi.
	Nħeġġek li tagħżel l-post u d-data tal-laqgħa tagħna.

	Jekk f'xi punt ma tridx tkompli tieħu sehem fir-riċerka tista' tagħmel dan fi kwalunkwe ħin.
	Infurmani jekk għandek bżonn aktar informazzjoni.

Nistenna mingħandek,

Tislijiet,

Antonella Micallef

Appendix 5 - Recruitment letter to organisations (English version)

Ms Antonella Micallef

Mobile number

E-mail address

Dear Sir/Madam,

I am a second year student reading for a Masters in Disability Studies at the University of Malta. I am writing in request of your approval to recruit participants from within your organisation in order to participate in a research study which will be carried out between 2018/2019.

I have chosen to conduct this study following my interest to study, in depth, the significance that young adults with autism attribute to the relationships formed with their peers. Thus, the main aim of this study is to explore the significance that young adults with autism attribute to their friendships. I consider this principle as fundamental in the study because such individuals are often studied upon but are rarely asked for their opinion. The study aims to promote empowerment of the research participants whilst giving them an opportunity to voice themselves.

The study shall require the participation of six young adults with autism, males and females, aged between eighteen to thirty-five years. Interested participants will be requested to participate in one-to-one interviews. It is worth noting that in order to achieve the participants' informed consent, a standard and easy-to-read letter in Maltese and English will be distributed to the participants, explaining the main aims of the study. Participants shall be informed that their participation is on a voluntarily basis and they are free to withdraw from the study at any given time and without providing a reason.

Thank you for your time and kind assistance,

I look forward to hearing from you,

Kindest regards,

Antonella Micallef

Appendix 6 - Recruitment letter to organisations (Maltese version)

Ms Antonella Micallef

Numru tal-mowbajl

Indirizz elettroniku

Għażiż/a Sinjur/a,

Jiena studenta tat-tieni sena f'kors ta' Masters fid-diżabilità fl-Università ta' Malta. Qed nikteb sabiex nistaqsi l-approvazzjoni tiegħek sabiex nirrekruta xi parteċipanti fi ħdan l-organizzazjoni sabiex jipparteċipaw fir-riċerka tiegħi li ser issir bejn l-2018/2019.

Għażilt li nwettaq din ir-riċerka għaliex għandi interess li nistudja fid-dettal is-siniffikat li żgħażagħ bl-awtiżmu jagħtu lill-ħbiberiji tagħhom. Għaldaqstant, l-għan ewlieni ta' din ir-riċerka huwa li nesplora s-sinifikkat li dawn iz-zgħażagħ jagħtu lir-relazzjonijiet tagħhom ma' sħabhom. Dan il-prinċipju huwa wieħed fundamentali għar-riċerka għaliex ħafna drabi dawn il-persuni ma jiġux mistoqsija għall-opinjonijiet tagħhom minkejja li jiġu studjati. L-istudju għandu l-għan li jippromwovi l-għoti tas-setgħa lill-parteċipanti filwaqt li jagħtihom l-opportunità li jesprimu lilhom infushom.

F'dan l-istudju neħtieġ il-parteċipazzjoni ta' sitt żgħażagħ b'awtiżmu, irġiel jew nisa, bejn it-tmintax u l-ħamsa u tlettin sena. Il-parteċipanti interessanti jiġu mitluba jipparteċipaw f'intervista miegħi. Ta' min jinnota li sabiex jinkiseb il-kunsens infurmat tal-parteċipanti, se titqassam ittra standard u oħra faċli biex tinqara bil-Malti u bl-Ingliż lill-parteċipanti, u tispjega l-għanijiet ewlenin tal-istudju. Il-parteċipanti għandhom ikunu infurmati li l-parteċipazzjoni tagħhom hija fuq bażi volontarja u huma liberi li jirtiraw mill-istudju fi kwalunkwe ħin partikolari u mingħajr ma jipprovdu raġuni.

Grazzi għall-ħin u l-assistenza tiegħek,

Nistenna minghandek,

Tislijiet,

Antonella Micallef

Appendix 7 - Consent form (English version)

Purpose of the research

The study will explore the experience of friendships of young adults with autism by focusing on their childhood and young adulthood experiences.

Duration of the research

The study will be carried out between 2018/2019. Participation in this research will require one interview for the duration of 1 hour.

Description of the procedure

The study shall require the participation of six young adults with autism, males and females, aged between eighteen to thirty-five years.

You will be requested to participate in one-to-one interviews.

You are encouraged to make use of additional material such as photographs that will facilitate your arguments during the interview.

In addition, you will also be invited to assist me in the formation of a booklet containing the responses of the interview.

The date and place for the interview will be chosen in accordance your preference.

Your participation will remain confidential and any potentially identifiable details will be removed.

The interview will be recorded and transcribed.

All information will be stored in a password protected computer.

The information provided will be used for dissertation purpose only and will be destroyed after the completion of data collection.

It is worth noting that participation is on a voluntarily basis and you are free to withdraw from the study at any given time and without providing a reason.

You should also note the Data Protection Act to access, rectify, and where applicable erase any data concerning you.

Risks

There are no perceived risks from participating in this study however given the nature of certain personal and sensitive questions, negative emotions may arise during the data generation and so I will seek assistance from psychologists or social workers, should the need arise.

Benefits

This study aims to promote your empowerment whilst giving them an opportunity to voice yourself.

It is hoped that the results shed light on the experiences of personas with autism and thus society can use this information to provide further support for individuals with similar diagnosis especially in the early years.

Furthermore, the information gathered from this research, with the help of willing participants will be transformed in a booklet to be distributed to the participants themselves, local schools and organisations.

This research is being done by Antonella Micallef under the supervision of Dr Anne-Marie Callus. Should you have any further queries, kindly contact me on (mobile number) or (e-mail address) or Dr Anne-Marie Callus on (e-mail address).

I, _____________________________, would like to participate in the research study by Antonella Micallef, entitled *The lived experiences of friendships of young adults on the autism spectrum*.

I am aware that the study will explore the experience of friendships amongst young adults with autism by focusing on childhood and young adulthood experiences.

I am aware that the interview will be recorded and transcribed for academic purposes.

I understand that my identity will not be revealed and all recorded material will be destroyed upon the completion of the research project.

I recognize that my participation in this research is on a voluntarily basis and I am free to withdraw from the study at any given time and without providing a reason.

I am informed about the aims of the study and had the opportunity to ask further questions in order to seek explanations.

I am satisfied by these conditions and consent to participate in this study.

____

Participant Signature

____

Researcher Signature

Date

Appendix 8 - Consent form (Maltese version)

L-intenzjoni tar-riċerka

Din ir-riċerka ser tesplora l-esperjenzi ta' żgħażagħ bl-awtiżmu u l-ħbieb tagħhom.

Iż-żmien tar-riċerka

Din ir-riċerkaserissirbejn l- 2018/2019. Il-parteċipazzjoni f'din ir-riċerka tinvolvi intervista waħda għal tul ta' siegħa.

Deskrizzjoni tal-proċedura

L-istudju jeħtieġ il-parteċipazzjoni ta' sitt żgħażagħ b'awtiżmu, irġiel u nisa, ta' etajiet bejn tmintax u ħamsa u tletin sena.

Int ser tintalab tipparteċipa f'intervista miegħi.

Int mħeġġeġ/mħeġġa tagħmel użu minn materjal addizzjonali bħal ritratti sabiex jiffaċilitaw l-argumenti tiegħek matul l-intervista.

Inti mistieden ukoll biex tgħinni fil-formazzjoni ta' ktejjeb li jkun fih ir-reazzjonijiet tal-intervista.

Id-data u l-post għall-intervista jiġu magħżula skond il-preferenza tiegħek.

Il-parteċipazzjoni tiegħek tibqa' kunfidenzjali u kwalunkwe dettalji li jistgħu jiġu identifikati se jitneħħew.

L-intervista ser jiġi rrekkordjat u transkritt.

L-informazzjoni kollha ser tinżamm f'kompjuter protett.

L-informazzjoni provduta se tintuża biss għall-għan tad-dissertazzjoni u se tinqered wara t-tlestija tal-ġbir tad-dejta.

Ta' min wieħed jinnota li l-parteċipazzjoni hija fuq bażi volontarja u inti liberu li tirtira mill-istudju fi kwalunkwe ħin partikolari u mingħajr ma tipprovdi raġuni.

Tajjeb li tkun taf ukoll id-drittijiet tiegħek skont id-Data Protection Act, sabiex taċċessa, tibdel u tħassar informazzjoni dwarek.

Riskji

M'hemm l-ebda riskji magħrufa milli tipparteċipa f'din ir-riċerka, iżda minħabba n-natura ta' mistoqsijiet personali u sensittivi tista' tħoss xi sentimenti negattivi. F'dan il-każ inti se tingħata għajnuna minn psikologi jew 'social workers'.

Benefiċji

L-għan ta' dan l-istudju huwa li jippromovi l-għoti tas-setgħa filwaqt li jagħtik l-opportunità biex titkellem dwar l-esperjenżi tiegħek.

Nittama li r-riżultati jixħtu dawl fuq l-esperjenzi ta' persuni bl-awtiżmu u għalhekk is-soċjetà tista' tuża din l-informazzjoni biex tipprovdi aktar appoġġ u servizzi għal individwi b'djanjosi simili speċjalment fi snin bikrija.

Barra minn hekk, l-informazzjoni miġbura minn din ir-riċerka, bl-għajnuna tal-parteċipanti, ser tiġi ttrasformata fi ktejjeb li ser jitqassam lill-parteċipanti nfushom, skejjel u organizzazzjonijiet lokali.

Din ir-riċerka qed issir minn Antonella Micallef taħt is-superviżjoni ta' Dr Anne-Marie Callus. Jekk ikollok aktar mistoqsijiet, jekk jogħġbok ikkuntattja fuq (numru tal-mowbajl) jew (indirizz elettroniku) jew Dr Anne-Marie Callus fuq (indirizz elettroniku).

Jiena, ______________________________, nixtieq nieħu sehem fir-riċerka magħmula minn Antonella Micallef, bl-isem ta' L-esperjenzi ta' ħbiberija ta' żgħażagħ bl-awtiżmu.

Jiena konxju/a li l-istudju se jesplora l-esperjenza tal-ħbiberija fost żgħażagħ bl-awtiżmu billi jiffoka fuq l-esperjenzi tat-tfulija u adulta.

Naf li l-intervista se tiġi rrekordjata u li ser jittieħdu n-noti għall-fini tar-riċerka.

Nifhem li l-identità tiegħi mhix ser tiġi żvelata u li kull materjal rrekordjat ser jitħassar ladarba titlesta r-riċerka.

Nirrikonoxxi li l-parteċipazzjoni tiegħi f'din ir-riċerka hija fuq bażi volontarja u ninsab liberu li nirtira mill-istudju fi kwalunkwe ħin u mingħajr ma nagħti raġuni.

Jiena infurmat/a dwar l-għanijiet ta' l-istudju u kelli l-opportunità li nistaqsi aktar mistoqsijiet sabiex infittex aktar spjegazzjonijiet.

Jien sodisfatt b'dawn il-kundizzjonijiet u nagħti l-kunsens tiegħi li nipparteċipa f'dan l-istudju.

____

Firma tal-Parteċipant

____

Firma tar-Riċerkatur

Data

Appendix 9 - Consent form (English version - Easy to read)

Consent Form

University of Malta	I, ________________ , would like to take part in the research study by Antonella Micallef, with the title *The lived experiences of friendships of young adults on the autism spectrum.*
	I know that the study will learn about the experience of young adults with autism and their friends.
	I know that the interview will be recorded and notes will be taken.
	I understand that my identity will not be made known and all recorded information will be destroyed once the research is ready.

	I understand that I will be taking part in this study because I want to and I am free to stop taking part in the study at any given time and without providing a reason.
	I know why this study is being done and I had the opportunity to ask more questions in order to understand better.
	I am happy by these conditions and would like to participate in this study.

_______________________ _______________________

Participant Signature Researcher Signature

Date

Appendix 10 - Consent form (Maltese version - Easy to read)

Formola ta' kunsens

University of Malta	Jiena, ____________________, nixtieq nieħu sehem fir-riċerka ta' Antonella Micallef, bl-isem ta' *L-esperjenzi ta' ħbiberija ta' żgħażagħ bl-awtiżmu.*
	Jiena fhimt li l-istudju se jkun dwar l-esperjenza tal-ħbiberija fost żgħażagħ bl-awtiżmu billi jiffoka fuq l-esperjenzi tat-tfulija u ħajja adulta.
	Naf li l-intervista se tiġi rrekordjata u li ser jittieħdu n-noti għar-riċerka.
	Nifhem li ismi mhux ser jinkiteb u li kull informazzjoni rrekordjata ser titħassar x'ħin titlesta r-riċerka.

	Jiena ser nieħu sehem f'din ir-riċerka għaliex irrid u naf li nista' nieqaf milli nkompli nieħu sehem fir-riċerka mill-istudju fi kwalunkwe ħin u mingħajr ma nagħti raġuni.
 ComputerHope.com	Jiena fhimt għaliex ser issir din ir-riċerka u kelli l-opportunità li nistaqsi aktar mistoqsijiet sabiex infittex aktar spjegazzjonijiet.
	Jien kuntent/a b'dawn il-kundizzjonijiet u naqbel li nieħu sehem f'dan l-istudju.

____________________________ _________________________

Firma tal-parteċipant Firma tar-riċerkatur

Data:

Appendix 11 - Interview questions (English version)

1. Can you describe a friend?

2. How do you enjoy spending your time?

3. Looking back at the activities you used to enjoy as a child, do you find yourself enjoying the same activities?

4.Who are your friends and why do you consider these people to be your friends?

5. How long have you been friends with these people?

6. Do you spend a lot of time with these people and how do you spend your time with them?

7. Who were your friends when you were a child?

8. What do you find fulfilling in your friendships and what challenges do you experience?

9. Do you prefer having a male or a female friend and why?

10. What factors contribute to establish and maintain a friendship?

11. How do you feel when you are with people you don't know?

12. Do you have any work colleagues/ATC friends/University friends or other acquaintances that you share personal experiences with?

13. In light of the fact that Malta is a bilingual country, does language create any barriers?

14. Having talked about friends, if I had to ask you to define a friend how would you describe a friend?

Appendix 12 - Interview questions (Maltese version)

1. Kif tiddeskrivi ħabib/a?

2. Kif tħobb tqatta' l-ħin tiegħek?

3. Meta tħarres lura u taħseb dwar l-attivitajiet li kont tieħu pjaċir tagħmel meta kont għadek tifel/tifla, illum il-ġurnata għadhom jinteressawk l-istess attivitajiet?

4.Min huma l-ħbieb tiegħek u għalfejn tikkunsidrahom bħala ħbieb?

5. Kemm ilek ħbieb magħhom?

6. Tgħaddi ħafna ħin magħhom u x'tagħmlu meta tkunu flimkien?

7. Min kienu l-ħbieb tiegħek meta kont għadek żgħir/a?

8. X'tikkunsidra bħala sodisfaċċenti fil-ħbiberiji tiegħek? X'inhuma d-diffikultajiet li tiltaqa' magħhom?

9. Tippreferi raġel jew mara bħala ħabib/a? Għala?

10. X'inhuma l-fatturi li jgħinu sabiex tibda ħbiberija ġdida u x'fatturi jgħinuk li żomm ħbiberiji tiegħek?

11. Kif tħossok meta tkun fil-preżenza ta' nies li ma tafx?

12. Għandek xi kollegi tax-xogħol/ħbieb miċ-ċentru/ħbieb mill-Università jew nies oħra li taqsam magħhom esperjenzi personali?

13. Il-fatt li Malta huwa pajjiż bilingwu, id-differenzi fil-lingwa joħolqulek diffikultajiet?

14. Issa li tkellimt miegħi dwar il-ħbieb, li jkolli nsaqsik kif tiddeskrivi ħabib/a, kif tiddiskrivih?