Sex Disabil
DOI 10.1007/s11195-017-9490-z

ORIGINAL PAPER

Sexual Well-Being and Quality of Life Among High-Functioning Adults with Autism

Shiri Pearlman-Avnion[1] · Noa Cohen[1] · Anat Eldan[1]

Abstract The current research addresses the effect that being in an intimate relationship has on quality of life and well-being among high-functioning young adults on the autism spectrum (HFA). The research included 31 participants: 14 involved in intimate relationships (HFA-R) and 17 not (HFA-NR). In this integrated (quantitative and qualitative) research, participants completed on-line questionnaires on demographics, quality of life and sexuality. We hypothesized that HFA-R will report higher quality of life and sexual well-being than HFA-NR. Further, a correlation was predicted between quality of life (including: satisfaction, productive capacity, social belonging/community inclusion and independence and empowerment) and sexual well-being (including: self-esteem, sexual depression and sexual preoccupation/sexual worries), especially among HFA-R. Despite the lack of significant differences in quality of life, differences were found in the indices' content areas. There was a higher sense of social belonging/community inclusion among HFA-R, and a positive correlation between sexual well-being and productive capacity among this group. A correlation was found between high productive capacity and low sexual worries among HFA-R, but not among HFA-NR. Contrary to expectations, a positive correlation was found between sexual well-being and satisfaction among HFA-NR, while no such correlation was found among HFA-R. The findings are discussed in the context of healthy sexuality and social development and acclimation of people with HFA. The results highlight the importance of promoting social dialogue and research on the subject.

Keywords High-functioning autism · Quality of life · Sexual well-being · Intimacy · Relationships · Israel

✉ Shiri Pearlman-Avnion
shiripe@telhai.ac.il

[1] Tel Hai College, Upper Galilee, Israel

Published online: 08 May 2017

Introduction

Sexuality, Sexual Well-Being and Quality of Life

The desire for intimacy is widespread among all people. Intimacy and a healthy sexual life may improve an individual's quality of life, facilitate participation in society, and provide opportunities to learn social skills in multiple domains, including but not limited to that of sexual functioning [1]. Sexuality and sexual well-being have an important role in healthy social development and adaptation of individuals into the society in which they live [2]. According to the World Health Organization, sexual health and well-being require a positive approach to sexuality [3]. Sexual well-being can be achieved with a partner or alone. The term 'sexual well-being' refers to an individual's subjective assessment of a wide range of physical, cognitive, emotional and social aspects of relations with oneself and with others. Sexual well-being includes sexual gratification, sexual knowledge, thoughts, feelings, personal experiences and approach to sexuality [4]. The quality of a sexual relationship is affected by sensory (physical) contact, degree of intimacy, and emotions regarding one's sexual partner [5].

Stephenson and Meston [5] differentiate sexual well-being into two evaluative categories: sexual satisfaction and sexual distress. Sexual satisfaction is one of the most important measures of sexual well-being, reflecting the quality and stability of an intimate relationship [6]. Sexual distress is a subjective assessment referring to feelings of worry, fear and frustration regarding one's sexual life [5]. The Sexuality Scale designed by Snell and Papini [7] differentiates between three sub-categories: self-esteem, sexual depression and sexual preoccupation (sexual worries).

Sexual well-being is considered to be related to quality of life. "Quality of life" is a multi-dimensional concept, comprising a person's evaluation and subjective perception of his/her mental well-being and satisfaction related to social, psychological and health realms [8]. According to the World Health Organization, quality of life is measured according to the individual's subjective evaluation, since it is influenced by a person's perceptions about his/her position in life in the social framework and cultural system in which he/she lives [9].

Schalock, Hoffman and Keith [10] developed a model of quality of life comprised of four realms: (1) *satisfaction*—degree of fulfillment of a need or desire, and feelings of contentment accompanying this realization; (2) *productive capacity*—productive creative work or work that contributes to the household or community; (3) *social belonging/community inclusion*—participation in community activities, use of community resources and establishment and development of social connections among people; (4) *independence and empowerment*—perception of the degree of ability to exert control over one's environment, willingness to look for opportunities to act, to exert personal control and to accept decisions (see also [11]). A link has been noted between quality of life and social relations [12], which are, in turn, related to sexual relations.

Sexuality and Sexual Well-Being Among Individuals with HFA

While sexuality and sexual development among people with typical neurological development ("Neurotypicals" or NTs) has been studied extensively, there is a lack of research dealing with special needs populations in general and in specific those on the autism spectrum [13–15]. Many early studies focused on pathological aspects, and suffered from

methodological weaknesses which limited the results [16]. In recent decades there has been a revival of interest in research on sexual well-being among individuals on the high-functioning end of the autism spectrum [1, 17].

According to the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* [18], Autism Spectrum Disorder (ASD) is a neuro-developmental disability revealed in early childhood, characterized by difficulties in communication, forming connections with others, and use of language and abstract concepts. Individuals with High-Functioning Autism (HFA) are characterized by normative intelligence, without significant cognitive delay, in which the disability is primarily expressed in difficulties related to social skills, non-verbal communication and stereotypical repetitive behaviors [19].

There is a prevailing perspective in the research literature that individuals with HFA face difficulties entering into and/or maintaining relationships that include a high degree of intimacy with a sexual partner [4, 20]. However, there are varying academic approaches regarding sexuality among people with HFA. Some theorists claim that the perception of sexuality among individuals with HFA inherently differs from that of NTs. For example, according to Rosqvist [21], people with HFA may feel stimulation or attraction to the sight or touch of objects which other people do not associate with sex. Gilmour, Schalomon and Smith [22] found that many people with HFA don't see sexual identity as a critical trait in choosing a sexual partner. Individuals on the autism spectrum may express inappropriate sexual behaviors, such as undressing or touching their private parts in public [23]. Dewinter et al. [13] found that adolescents with HFA were more tolerant of homosexuality, in comparison with NTs, which may be due to various mechanisms such as lower sensitivity to social sexual norms or higher tolerance for people who are different.

Other researchers argue, in contrast, that the difficulties regarding sexuality that seem to stem from the disability actually come from society, processes of socialization and sexual education. Social norms and standards regarding romantic relationships and sexuality present difficulties for people on the autism spectrum, not lack of interest [24]. For example, Strunz et al. found the majority of interviewees involved in an outpatient clinic for adults on the autism spectrum had been involved in romantic relationships and had a desire to be in such relationships, but faced difficulty in initiating and maintaining these relationships. Greater success in maintaining a relationship and satisfaction with it was expressed by individuals involved with a partner also on the autism spectrum, perhaps because they better understand each others' needs, such as for solitude or routine, characteristic to people with HFA [20].

Perceptions of Intimacy and Sexuality Among Individuals with HFA

Individuals on the autism spectrum desire social connections, including romantic and intimate relations [25]. However, while many HFA individuals do report a positive sense of sexual well-being, their sense of sexual well-being is low in comparison with that of NTs [6]. They often lack the necessary social skills and knowledge necessary to successfully initiate relationships [14]. Stokes and Kaur [23] found that sexual behavior is a function of both age and social-sexual skills, and since people with HFA tend to be less involved in social activities than are NTs they are similarly likely to have fewer sexual experiences. As a result, healthy sexual functioning is a challenge for them [24]. Negative past experiences individually and collectively hamper their efforts to develop romantic and intimate relationships [26].

Further, it has been found that individuals with HFA experience higher anxiety levels regarding romantic and sexual experiences than NTs. People with HFA express great

concern regarding the future, including difficulty finding a life partner. They worry about incorrectly interpreting social cues regarding sex, and other people misinterpreting their behaviors. People with HFA report that they often find it difficult to distinguish socially acceptable courtship behaviors from those the sought-after person may see as invasion of privacy, and as a result their behaviors are sometimes interpreted as sexual harassment [16, 27]. Their fears and anxieties may prevent them from creating romantic connections. Other core characteristics of HFA which present obstacles to intimacy include lack of flexibility towards one's partner [4], the tendency to engage in limited areas of interest, and difficulty understanding the needs of others [28].

Research based on parental reports found a significant gap in the social capabilities and sexual behavior of adolescents with HFA compared with NTs [23, 29]. By comparing parental reports of 25 adolescents and adults on the autism spectrum with those of 38 typical adolescents and adults, the overall level of social functioning was found to be the most significant predictor of romantic functioning among adolescents and adults on the autism spectrum. The parents of those with HFA were more likely to report that their children had difficulties initiating romantic relations as compared with their peers, were more likely to engage in inappropriate courtship behaviors, and tended to extend courtship behaviors over a longer average period of time as compared with the control group. They reported that the autistic adolescents and adults relied less on peers and friends for learning about romantic relations, and were more inclined to pay attention to celebrities, strangers, colleagues or former partners [29]. At the same time, while adolescents' opinions regarding sexuality are often affected by social media networks [15], adolescents with HFA have lower use of social media networks in general, and for creating romantic relationships in particular [29]. A study among parents of boys with HFA found the parents often underestimate their sons' sexual experiences, both with partners and alone [30]. Another study of parents of adolescent girls with HFA identifies challenges the parents and girls face regarding puberty, friendship and dating [31].

A survey by Byers et al. [1] found that average-intelligence adults with HFA report a high level of solitary sexual activity, while only a small percentage have sexual relations with a partner. However a study of 205 HFA adults involved in romantic relationships of at least 3 months found that over three-quarters of participants reported reciprocal sexual and romantic activity, including physical contact such as hugging and kissing and emotional aspects such as sharing feelings [6].

As among the general population, differences have been found between males and females with HFA in relation to sexual relations and behavior. While both genders report a desire to be in a shared sexual relationship and there was no significant difference in sexual knowledge, the surveyed HFA males reported a higher sense of sexual well-being and sexual satisfaction than HFA females, while females expressed more anxiety and reported greater difficulties in the realm of sexuality [1]. One possible explanation for this refers to the widespread societal perception that females are expected to express affection and emotions more readily than males, which may be problematic for women on the autism spectrum [21]. Another possible, and possibly better explanation for these findings may come from by Miller and Byer's [32] research among the general population, which found that males' perceptions of their partner's desires correlate more strongly with sexual stereotypes (what it is accepted to think that women want) than with the desires actually reported by their partners. As noted above, HFA rely less on peers or direct communication in order to form impressions of what a partner wants [29]; this may be truer for males.

Quality of Life Among Individuals with HFA

Being on the autism spectrum doesn't only affect sexual well-being. Individuals with HFA report a lower overall quality of life compared with other special needs populations [33, 34]. Among adults with HFA low quality of life correlates with dissatisfaction with work, education, and intimate relationships [35].

A correlation has been found between the number of social connections individuals with HFA have and their overall level of emotional functioning; it is an especially helpful predictor of self-esteem, depression and anxiety [36]. In relation to the general population, individuals with HFA create fewer social connections and experience greater feelings of social isolation [35, 37]. Therapy may provide assistance in adapting social skills, and guided intervention is reflected in more positive self-reports of quality of life among individuals with HFA [37]. Additional findings show a significant decline in feelings of isolation and improved social skills following appropriate treatment, and from social frameworks and social connections that provide positive experiences [35, 38, 39].

Interestingly, a difference was found between reports on quality of life from adults with ASD and the reports made by their parents. In reports by mothers of autistic children, the most predictive indicators for quality of life were the level of independence and empowerment in daily activity and health status, while in reports by adults with ASD the level of stress and previous life experiences were better indicators of quality of life [39]. Similarly, a high level of anxiety and a subjective perspective of events as negative were found to be predictors of a low quality of life in self-reports by adults with ASD [40].

Traumatic events such as sexual abuse affect functioning and life evaluation. Sexual abuse and sexual assault may lead to serious regression, decline of communication skills, increased risk of developing mental illnesses, sleep and eating disorders, and overall a significant decline in quality of life [41]. People with HFA have been found to be at higher risk for sexual abuse compared with the rest of the population. Factors in the social environment impact risk for sexual abuse [27]. One explanation is the apparent difficulty people on the autism spectrum have in interpreting social cues and relying on past knowledge, which can impact their ability to distinguish between people who can be trusted and those who cannot [4, 41]. Further, there is a tendency in society to relate to people with special needs as asexual or 'eternal children'. This creates create gaps between their real needs, the way they are treated, and their accurate reception of information they receive [16]. Such gaps may lead to danger of sexual abuse in the absence of adequate supervision [27]. Both the increased risk being victims of sexual abuse and the potential for engagement in behaviors perceived by society to be inappropriate highlight the need for sexual education tailored to autistic adolescents [42–44]. When sexuality among autistic adolescents is ignored problems are more likely to arise, whereas sexual education tailored to their needs can increase the likelihood of sexual well-being [45].

Research Hypotheses

The current research examines sexual well-being and quality of life among HFA. Data is gathered from the HFA adults themselves, not parental reports (see recommendation of [26]). We compare perceptions of quality of life and sexual well-being among adults with HFA who were in an intimate relationship at the time of the study (HFA-R) and those who were not in intimate relationships at the time of the study (HFA-NR). We hypothesize that:

1. Quality of life among HFA-R will be higher than that of HFA-NR.
2. Sexual well-being of HFA-R will be higher than that of HFA-NR.
3. There is a positive correlation between sexual well-being and quality of life among HFA-R, but not among HFA-NR.

Methods

Study Design

To examine these hypotheses we designed a study integrating quantitative and qualitative methods. We compared the two groups regarding quality of life and sexual well-being, and investigated correlations between sexual well-being and quality of life of participants, such that "relationship status" serves as an intervening variable.

Study Population

The research population included 31 participants diagnosed as high-functioning autistic. Participants included only those whose diagnosis had been authorized by a professional in the fields of psychiatry and healthcare, as required by the Director General of the State of Israel's Ministry of Health [46]. There were 18 males, 11 females and 2 participants who defined their gender as 'other'. Their ages ranged from 17 to 62 years old (M = 27.79). About a third (32.3%) of them holds academic degrees. Almost half live with their parents. At the time that the questionnaire was completed, 45.2% were in an intimate relationship (average age M = 26.27) and 54.8% were not (average age M = 26.27). Table 1 shows the socio-demographic characteristics of the total sample.

Table 1 Socio-demographic characteristics of the total sample (N = 31)

Variable	Values	Frequency	%
Gender	Female	11	35.5
	Male	18	58.1
	Other	2	6.5
Residence	With parents	14	45.2
	Independent residence	5	16.1
	Shared residence with roommates	5	16.1
	Other	7	22.6
Education	Less than high-school	1	3.2
	High school without matriculation	6	19.4
	High school with matriculation	12	38.7
	Secondary non-academic education	1	3.2
	Higher education	10	32.3
	Other	1	3.2
Relationship status	Currently in relationship	14	45.2
	Currently not in relationship	17	54.8

Age—Average: 27.79, SD: 11.299, Age range: 17–62

Age at diagnosis—Average: 16.24, SD: 11.798, Age range: 3–47

Research Tools

1. *Demographic questionnaire* This questionnaire collected data on gender, age, place of residence, education, confirmation of formal diagnosis, age at time of diagnosis, year of diagnosis, and relationship status.
2. *Quality of life questionnaire* (QLQ) [10] This questionnaire was adapted to a population with disabilities. The Hebrew version of this questionnaire was taken from Noyman [47]. A section pertaining to each of the four content areas (satisfaction, productive capacity, social belonging/community inclusion, and independence and empowerment) received a separate score. Each area includes 10 questions (total of 40). Each question has three possible answers, earning scores of 1–3 points. Therefore scores for each content area range between 10 points and 30 points, if all the questions are answered. The measure of quality of life is based on the total scores received in the four content areas. A higher score indicates perception of a better quality of life. Internal reliability for this questionnaire is $\alpha = 0.9$ [10]. The reliability for each content area is: satisfaction—$\alpha = 0.74$; productive capacity—$\alpha = 0.65$; social belonging/community inclusion—$\alpha = 0.72$; independence and empowerment—$\alpha = 0.68$.
3. *Sexual well-being questionnaire* This questionnaire, suited for general research on sexuality, is divided into three sub-categories, following the Sexuality Scale [7]: self-esteem, sexual depression and sexual worries. The Hebrew version of this questionnaire was taken from [48]. Scores were compiled from individual items in each area. Subjects responded to questions according to a five-point Likert scale in which $+2$ indicates *strongly agree*, $+1$ indicates *somewhat agree*, 0 indicates *no opinion*, -1 indicates *somewhat disagree* and -2 indicates *do not agree at all*. A higher score indicates a more positive self-perception of sexual well-being. This questionnaire has been found to be reliable and valid. For the present study, the reliability of the self-esteem scale was $\alpha = 0.802$, for the scale of sexual depression $\alpha = 0.799$, and $\alpha = 0.876$ for sexual worries.

Research Process

The research questionnaires were posted and distributed via internet websites for people on the autism spectrum in Israel. During a preliminary distribution of three pilot questionnaires, we received feedback from several participants that the questionnaires were not appropriate for the autistic population. After subsequent consultation with experts in the field of autism in Israel, we removed two questionnaires: a socialization questionnaire and a questionnaire on sexual satisfaction aimed at people in intimate relationships. These were replaced with the sexual well-being questionnaire which is also appropriate for people who are not in relationships. Additionally, we added a text box to allow participants the opportunity to freely express their thoughts, providing qualitative data.

At the beginning of the research there were 48 participants. Of these, 17 did not continue because they did not provide details about their diagnosis, or the details they provided of their diagnosis did not correspond to the definition of the Director General of the Israel Ministry of Health [46]. Of the 31 remaining participants, only 23 answered the sexual well-being questionnaire.

Results

Table 2 shows averages and standard deviations of the study variables on quality of life study (based on the QLQ) and the four areas of which it is composed: satisfaction; productive capacity; social belonging/community inclusion; and independence and empowerment, and for sexual well-being and the three areas of which it is composed (based on the Sexuality Scale): self-esteem, sexual depression, and sexual preoccupation.

Hypothesis 1: Quality of Life To test the first hypothesis, that quality of life of will be higher among HFA-R than among HFA-NR, we compared the measures of quality of life according to relationship status. The comparison was made by *T* tests for independent design registrations (Independent *T* tests). Table 3 shows the averages and standard deviations of the quality of life variables by status and double *T* test results (N = 31).

It can be seen that there is no significant difference found in the average measure of quality of life for HFA-R and HFA-NR ($t_{(20)} = .27; p > .05$). Thus, the hypothesis was not verified. However, a comparison conducted on the basis of the various content areas found a significant difference in the measure for social belonging/community inclusion ($t_{(29)} = 1.74$; $p < .05$(. HFA-R reported a higher level of social belonging/community inclusion (M = 21.42, SD = 3.45) than HFA-NR (M = 19.17, SD = 3.67). Additionally, a trend approaching the required level of significance for the measure of independence and empowerment can be seen. HFA-R report a higher feeling of independence and empowerment (M = 18.14, SD = 2.10) than HFA-NR (M = 16.94, SD = 2.30), ($t_{(29)} = 1.50$; $p = .07$).

Hypothesis 2: Sexual Well-Being To test the second hypothesis, that sexual well-being of HFA-R will be higher than that of HFA-NR, we conducted a comparison of the measures of sexual well-being according to relationship status. Table 4 shows the average and standard deviations of measures of sexual well-being by double status and results of *T* tests (N = 23).

Table 2 Analysis of variance of quality of life and sexuality scale (N = 31)

Variable	Level of measurement	Item number	*M*	*SD*	*MIN*	*MAX*
Quality of life						
Quality of life (QLQ)	1–3	40	80.54	9.85	56	98
Satisfaction	1–3	10	20.19	4.47	11	29
Productive capacity	1–3	10	22.95	4.029	13	28
Independence and empowerment	1–3	10	17.48	2.26	12	21
Social belonging/community inclusion	1–3	10	20.19	3.70	11	27
Sexuality scale						
Sexuality scale	1–5	27	7.73	14.24	−18	38
Self-esteem	1–5	9	0.86	5.97	−16	11
Sexual depression	1–5	9	4.3	6.05	−11	13
Sexual preoccupation	1–5	6	2.56	8.17	−15	16

Table 3 Results of *T* test and descriptive statistics for quality of life by relationship status (N = 31)

Variable	HFA-R (*N = 14*)		HFA-NR (*N = 17*)		*T*	*p* value
	M	*SD*	*M*	*SD*		
Quality of life	81.08	7.90	79.90	12.23	.27	.39
Satisfaction	20.35	3.45	20.05	5.27	.18	.42
Productive capacity	22.08	3.44	24.00	4.59	−1.11	.13
Independence and empowerment	18.14	2.10	16.94	2.30	1.50	.07
Social belonging/community inclusion	21.42	3.45	19.17	3.67	1.74	.04*

* $p < .05$

Table 4 Results of *T* test and descriptive statistics for sexuality scale by relationship status (N = 23)

Variable	HFA-R (*N = 14*)		HFA-NR (*N = 17*)		*T*	*p* value
	M	*SD*	*M*	*SD*		
Sexuality Scale	10.50	14.72	5.61	14.08	.80	.21
Self-esteem	2.60	5.39	−.46	6.25	1.23	.11
Sexual depression	5.70	5.61	3.23	6.37	.96	.17
Sexual preoccupation	2.20	7.28	2.84	9.08	−.18	.42

* $p < .05$

No significant difference was found in the average measure of sexual well-being for HFA-R and HFA-NR ($t_{(21)} = .80$; $p > .05$). Therefore, the second hypothesis is refuted—we found no positive impact of an intimate relationship on perception of sexual well-being.

Hypothesis 3: Sexual Well-Being and Quality of Life To test the third hypothesis, that a positive correlation will be found between sexual well-being and quality of life among HFA-R but not among HFA-NR, we carried out a test using Pearson's Correlations between quality of life variable including its four content areas, and the sexual well-being variable including its three content areas. This test was conducted separately on the two groups (split file) for HFA-R and HFA-NR.

Table 5 presents the Pearson correlations between quality of life and sexual well-being according to relationship status (N = 23).

No significant correlation was found between the measures for HFA-R (R = .367, ns), but the trend was in a positive direction: as sexual well-being rose, the measure of quality of life also rose. On the other hand, a negative non-significant correlation was found among HFA-NR (R = −.109, ns). The third hypothesis was refuted.

Some additional correlations between the measures according to relationship status were found.

1. A significant and strong positive correlation between the measure of productive capacity and sexual well-being among HFA-R (R = .776: $p < .05$), but not among HFA-NR (R = .077, ns).

Table 5 Pearson correlations between quality of life and sexuality well-being by relationship status (N = 23)

	Quality of life	Satisfaction	Productive capacity	Independence and empowerment	Social belonging/community integration
HFA-R (N = 10)					
Sexual well-being	.367	.315	.776*	−.008	.130
Self-esteem	.308	.437	.463	−.065	−.160
Sexual depression	.200	.319	.589	−.250	.086
Sexual preoccupation	.368	.067	.798**	.224	.315
HFA-NR (N = 13)					
Sexual well-being	−.109	.529*	.077	−.040	−.019
Self-esteem	.397	.434	.438	.450	−.200
Sexual depression	.002	.352	.195	−.266	−.086
Sexual preoccupation	−.484	.274	−.392	−.185	.170

** $p < .01$; * $p < .05$

2. A strong, significant positive correlation between the measures of productive capacity and sexual worries among HFA-R (R = .798, $p > .01$). As a high score reflects a more positive self-perception, these findings indicate that among HFA-R, as sexual preoccupation and sexual worries decline productive capacity increases. No similar correlation was found among HFA-NR (R = −.392, ns).
3. In the opposition to the research hypothesis, a significant and moderately strong positive correlation was found between sexual well-being and satisfaction among HFA-NR (R = .529, $p < .05$) but not among HFA-R (R = .315, ns).

Qualitative Findings

Some participants responded to the open question section in the questionnaire. While the comments are idiosyncratic, and thus difficult to integrate with the quantitative data, they do give insights into participants' perspective on intimacy, as well are feedback on the research process itself. Some examples of the comments received were:

I don't publicize that I have Asperger's Syndrome because society isn't aware of it and I'm afraid of a 'social pogrom'

I didn't know what to answer because I don't have any idea what 'success' is. Many questionnaire items didn't include possible answers that describe my situation. For example, my neighbor treats me fairly and appropriately, but from my perspective being 'fair' simply means ignoring me. I never meet others. I don't have friends and no-one visits me.

I don't have the ability (so far) to experience an orgasm, and this affects my perception of sex. I also have specific fears of sex due to non-sexual abuse (forced feeding) which I experienced in childhood.

Discussion

This research filled a gap in the literature by examining how being in an intimate relationship affects sexual well-being and perception of quality of life among individuals with HFA, using direct reports. Based on previous research using parental reports [1, 49], which indicated a beneficial impact of being in an intimate relationship on quality of life and on approach to sexuality among individuals with HFA, we hypothesized that the status of being in a relationship would have a positive impact on quality of life and sexual well-being among individuals with HFA.

However, the current research also did not find a difference in sexual well-being between HFA-R and HFA-NR. On the one hand, it is possible that results from a gap between the direct reports used in the current study and parental reports used in previous research [1, 49]. On the other hand, it may be a result of the small sample size; there is a need to expand the research to enable generalization and validation. This point emphasizes the importance of research among the special needs population to survey a larger number of participants who are sexually active [1, 16].

Similarly, this research did not find a significant difference in measures of quality of life between those who were in an intimate relationship at the time of the study and those who were not. Nevertheless, HFA-R did report higher levels of social participation. The findings of the current research correspond with the assessment that feelings of social belonging/community inclusion predict ability to initiate a romantic relationship [29].

A similar trend was found regarding the content issue of independence and empowerment: HFA-R report stronger feelings of independence and empowerment than HFA-NR. Thus, the current research demonstrates that an intimate relationship is indeed connected with independence and empowerment. These findings strengthen the claim of Hong et al. [39] that the level of independence and empowerment is an accurate indicator predicting quality of life.

While no correlation was found between quality of life and sexual well-being among either HFA-R or HFA-NR, we did identify important correlations between the various content areas of which these two indices are comprised. The significant positive correlation between productive capacity and sexual well-being among HFA-R indicates the nature of the contribution of intimacy to an individual's life. This finding is in line with that of Byers et al. [1], that a romantic relationship may be used as a tool for learning life skills. Being in a romantic relationship accompanied by a perception of sexual well-being may strengthen the feeling of productive capacity among individuals with HFA.

The negative correlation between sexual worries and productive capacity which was found among HFA-R is interesting, particularly in light of the World Health Organization's [3] position that sexuality plays an important role in individuals' healthy development and adaptation to society. These findings are also consistent with the assertion that dissatisfaction among individuals with HFA at work, in social and educational frameworks and in intimate relationships predicts lower quality of life [35].

In opposition to the research hypotheses, we found a positive correlation between sexual well-being and satisfaction among HFA-NR but not among HFA-R. Among the group of

those not in relationships, reported satisfaction rose as sexual involvement decreased. This seems to indicate that there is no need to be in an intimate relationship in order to feel sexual satisfaction and that relationship status is not the sole criterion for sexual well-being, satisfaction, contentment or personal fulfillment. This finding strengthens the argument that there is a wide spectrum of types of sexual involvement and sexual perceptions that differ from typical sexuality [21]. This is consistent with Gilmour et al. [22] who found that many people with HFA do not see sexual identity and sexual involvement as critical components of their personal identity.

Research Limitations

Despite our attempts to build a reliable and valid research sample, our sample was small ($N = 31$) and an even smaller number completed the sexual well-being questionnaire ($N = 23$). Further, as the method of distribution was via the internet, only people who use the internet could be represented. At the same time, this enabled participants to openly express themselves, which perhaps would not have been possible through direct interviews with people on the autism spectrum. Some of the qualitative responses were instructive, even when they concerned the style of the research, and such responses led to changes in the actual research process.

In light of these initial findings, we are convinced that there is a need to continue to investigate the issue among a larger representative study population. The qualitative comments received indicate a need to formulate the questions in such a way that the issue of sexuality can be investigated on a clinical level, rather than only from the perspective of the participating individuals. Thus, research tools should be used which enable deeper investigation of the clinical and qualitative aspects of the issue. Further, future studies should distinguish between males and females on the high-functioning autism spectrum. Additionally, future research should investigate the impact of the participants' living situation (with parents or independently) as an intervening variable which may affect sexual well-being and quality of life.

Conclusions

The present findings highlight the need for further open and direct inquiry of the challenges, and especially, the benefits of intimate relationships among HFA adults, using larger samples and a greater variety of research tools, both qualitative and quantitative. The interesting gap between parental and self-reports of people on the autism spectrum raises the need for further examination and comparison of these two perspectives. Research on this important topic should be conducted in cooperation with people in the autistic community who can direct the researchers towards more accurate and effective methods of examination.

Other variables such as gender difference and residential environment should be considered. The present research shows the positive aspects of being in intimate relationships for people with HFA: the correlation with independence and empowerment, the positive correlation between productive capacity and sexual well-being, and the negative correlation between sexual worries and productive capacity. The fact that satisfaction among HFA-NR rose as sexual involvement decreased indicate diverse perceptions of what

constitutes sexual satisfaction and the need (or not) of being in a relationship to achieve it. These findings could direct therapists working with autistic adolescents and adults with HFA towards a different and more self-regulating perspective regarding sexual well-being. At this point, the findings are correlative. In order to predict cause and effect, a longitudinal examination is needed.

Compliance with Ethical Standards

Conflict of interest Shiri Pearlman-Avnion, Noa Cohen and Anat Eldan declares that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of Tel Hai Academic College and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Human and Animals Rights This article does not contain any studies with animals performed by any of the authors.

Informed Consent Informed consent was obtained from all individual participants included in the study.

References

1. Byers, E.S., Nichols, S., Voyer, S.D.: Challenging stereotypes: sexual functioning of single adults with high functioning autism spectrum disorder. J. Autism Dev. Disord. **43**, 2617–2627 (2013). doi:10.1007/s10803-013-1813-z
2. SIECUS. Sexuality of Persons with Disabilities. Sexuality Information and Education Council of the United States. (2010). Retrieved 27 from Jan 2010. http://www.siecus.org
3. World Health Organization. Defining Sexual Health. World Health Organization (2006) Retrieved from http://www.who.int/reproductivehealth/publications/sexual_health/defining_sexual_health.pdf
4. Urbano, M.R., Polychronopoulos, G.M.B., Hartmann, K., Deutsch, S.I., Dorbin, V.: Relationships, Sexuality, and Intimacy in Autism Spectrum Disorders. INTECH Open Access Publisher, London (2013)
5. Stephenson, K.R., Meston, C.M.: The conditional importance of sex: exploring the association between sexual well-being and life satisfaction. J. Sex Marital Ther. **41**, 25–38 (2015). doi:10.1080/0092623X.2013.811450
6. Byers, E.S., Nichols, S.: Sexual satisfaction of high-functioning adults with autism spectrum disorder. Sex. Disabil. **32**, 365–382 (2014). doi:10.1007/s11195-014-9351-y
7. Snell, W., Papini, D.: The sexuality scale: an instrument to measure sexual-esteem, sexual-depression, and sexual-preoccupation. J. Sex. Res. **26**, 256–263 (1989). doi:10.1080/00224498909551510
8. Danckaerts, M., Sonuga-Barke, E.J., Banaschewski, T., Buitelaar, J., Döpfner, M., Hollis, C., Taylor, E.: The quality of life of children with attention deficit/hyperactivity disorder: a systematic review. Eur. Child Adolesc. Psychiatry **19**, 83–105 (2010). doi:10.1007/s00787-009-0046-3
9. WHOQOL Group: The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. Soc. Sci. Med. **41**, 1403–1409 (1995). doi:10.1016/0277-9536(95)00112-K
10. Schalock, R.L., Hoffman, K., Keith, K.D.: Quality of Life Questionnaire. International Diagnostic Systems Publishing Corporation, Orland Park (1993)
11. Schalock, R.L., Bonham, G.S., Verdugo, M.A.: The conceptualization and measurement of quality of life: implications for program planning and evaluation in the field of intellectual disabilities. Eval. Progr. Plan. **31**, 181–190 (2008). doi:10.1016/j.evalprogplan.2008.02.001
12. Van der Horst, M., Coffé, H.: How friendship network characteristics influence subjective well-being. Soc. Indic. Res. **107**, 509–529 (2012). doi:10.1007/s11205-011-9861-2
13. Dewinter, J., Vermeiren, R., Vanwesenbeeck, I., Lobbestael, J., Van Nieuwenhuizen, C.: Sexuality in adolescent boys with autism spectrum disorder: self-reported behaviours and attitudes. J. Autism Dev. Disord. **45**, 731–741 (2015)
14. Hellemans, H., Colson, K., Verbraeken, C., Vermeiren, R., Deboutte, D.: Sexual behavior in high-functioning male adolescents and young adults with autism spectrum disorder. J. Autism Dev. Disord. **37**, 260–269 (2007). doi:10.1007/s10803-006-0159-1

15. Renty, J., Roeyers, H.: Individual and marital adaptation in men with autism spectrum disorder and their spouses: the role of social support and coping strategies. J. Autism Dev. Disord. **37**, 1247–1255 (2007). doi:10.1007/s10803-006-0268-x
16. Dewinter, J., Vermeiren, R., Vanwesenbeeck, I., van Nieuwenhuizen, C.: Autism and normative sexual development: a narrative review. J. Clin. Nurs. **22**, 3467–3483 (2013). doi:10.1111/jocn.12397
17. Hough, S.: From the editor of sexuality and disability: hot topics in the field of sexuality. Sex. Disabil. (2012). doi:10.1007/s11195-012-9283-3
18. American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders (DSM-5). American Psychiatric Publication, New York (2013)
19. Noterdaeme, M., Wriedt, E., Höhne, C.: Asperger's syndrome and high-functioning autism: language, motor and cognitive profiles. Eur. Child Adoles. Psychiatry **9**, 475–481 (2010). doi:10.1007/s00787-009-0057-0
20. Strunz, S., Schermuck, C., Ballerstein, S., Ahlers, C.J., Dziobek, I., Roepke, S.: Romantic relationships and relationship satisfaction among adults with Asperger Syndrome and high-functioning autism. J. Clin. Psychol. **73**, 113–125 (2017). doi:10.1002/jclp.22319
21. Rosqvist, H.B.: Becoming an 'autistic couple': narratives of sexuality and couplehood within the Swedish autistic self-advocacy movement. Sex. Disabil. **32**, 351–363 (2014). doi:10.1007/s11195-013-9336-2
22. Gilmour, L., Schalomon, P.M., Smith, V.: Sexuality in a community based sample of adults with autism spectrum disorders. Res. Autism Spect. Disord. **6**, 313–318 (2012). doi:10.1016/j.rasd.2011.06.003
23. Stokes, M.A., Kaur, A.: High-functioning autism and sexuality a parental perspective. Autism **9**, 266–289 (2005). doi:10.1177/1362361305053258
24. Kellaher, D.C.: Sexual behavior and autism spectrum disorders: an update and discussion. Curr. Psychiatry Rep. **17**, 1–8 (2015). doi:10.1007/s11920-015-0562-4
25. Hénault, I.: Asperger's Syndrome and Sexuality: From Adolescence Through Adulthood. Jessica Kingsley Publishers, London (2015)
26. Mehzabin, P., Stokes, M.A.: Self-assessed sexuality in young adults with high-functioning autism. Res. Autism Spect. Disord. **5**, 614–621 (2011). doi:10.1016/j.rasd.2010.07.006
27. Sevlever, M., Roth, M.E., Gillis, J.M.: Sexual abuse and offending in autism spectrum disorders. Sex. Disabil. **31**, 189–200 (2013). doi:10.1007/s11195-013-9286-8
28. Travers, J., Tincani, M.: Sexuality education for individuals with autism spectrum disorders: critical issues and decision making guidelines. Educ. Train. Autism Dev. Disab. **45**, 284–293 (2010)
29. Stokes, M., Newton, N., Kaur, A.: Stalking, and social and romantic functioning among adolescents and adults with autism spectrum disorder. J. Autism Dev. Disord. **37**, 1969–1986 (2007). doi:10.1007/s10803-006-0344-2
30. Dewinter, J., Vermeiren, R.R.J.M., Vanwesenbeeck, I., Van Nieuwenhuizen, C.: Parental awareness of sexual experience in adolescent boys with autism spectrum disorder. J. Autism Dev. Disord. **46**, 713–719 (2016)
31. Cridland, E.K., Jones, S.C., Caputi, P., Magee, C.A.: Being a girl in a boys' world: investigating the experiences of girls with autism spectrum disorders during adolescence. J. Autism Dev. Disord. **44**, 1261–1274 (2014). doi:10.1007/s10803-013-1985-6
32. Miller, S.A., Byers, E.S.: Actual and desired duration of foreplay and intercourse: discordance and misperceptions within heterosexual couples. J. Sex Res. **41**, 301–309 (2004). doi:10.1080/00224490409552237
33. Barneveld, P.S., Swaab, H., Fagel, S., van Engeland, H., de Sonneville, L.M.: Quality of life: a case-controlled long-term follow-up study, comparing young high-functioning adults with autism spectrum disorders with adults with other psychiatric disorders diagnosed in childhood. Compr. Psychiatry **55**, 302–310 (2014). doi:10.1016/j.comppsych.2013.08.001
34. Van Heijst, B.F., Geurts, H.M.: Quality of life in autism across the lifespan: a meta-analysis. Autism **19**, 158–167 (2015). doi:10.1177/1362361313517053
35. Cottenceau, H., Roux, S., Blanc, R., Lenoir, P., Bonnet-Brilhault, F., Barthélémy, C.: Quality of life of adolescents with autism spectrum disorders: comparison to adolescents with diabetes. Eur. Child Adoles. Psychiatry **21**, 289–296 (2012). doi:10.1007/s00787-012-0263-z
36. Whitehouse, A.J., Durkin, K., Jaquet, E., Ziatas, K.: Friendship, loneliness and depression in adolescents with Asperger's syndrome. J. Adolesc. **32**, 309–322 (2009). doi:10.1016/j.adolescence.2008.03.004
37. Locke, J., Ishijima, E.H., Kasari, C., London, N.: Loneliness, friendship quality and the social networks of adolescents with high functioning autism in an inclusive school setting. J. Res. Spec. Educ. Needs **10**(2), 74–81 (2010). doi:10.1111/j.1471-3802.2010.01148.x

38. Gantman, A., Kapp, S.K., Orenski, K., Laugeson, E.A.: Social skills training for young adults with high-functioning autism spectrum disorders: a randomized controlled pilot study. J. Autism Dev. Disord. **42**, 1094–1103 (2012). doi:10.1007/s10803-011-1350-6
39. Hong, J., Bishop-Fitzpatrick, L., Smith, L.E., Greenberg, J.S., Mailick, M.R.: Factors associated with subjective quality of life of adults with autism spectrum disorder: self-report versus maternal reports. J. Autism Dev. Disord. **46**, 1368–1378 (2016). doi:10.1007/s10803-015-2678-0
40. Bishop-Fitzpatrick, L., Mazefsky, C.A., Minshew, N.J., Eack, S.M.: The relationship between stress and social functioning in adults with autism spectrum disorder and without intellectual disability. Autism Res. **8**, 164–173 (2015). doi:10.1002/aur.1433
41. Brown-Lavoie, S.M., Viecili, M.A., Weiss, J.A.: Sexual knowledge and victimization in adults with autism spectrum disorders. J. Autism Dev. Disord. **44**, 2185–2196 (2014). doi:10.1007/s10803-014-2093-y
42. Curtiss, S.L., Ebata, A.T.: Building capacity to deliver sex education to individuals with autism. Sex. Disabil. **34**, 27–47 (2016). doi:10.1007/s11195-016-9429-9
43. Travers, J., Tincani, M.: Sexuality education for individuals with autism spectrum disorders: critical issues and decision making guidelines. Educ. Train. Autism Dev. Disabil. **45**, 284–293 (2010)
44. Mackenzie, R., Watts, J.: Sexual health, neurodiversity and capacity to consent to sex. Tizard Learn. Disabil. Rev. **18**, 88–98 (2013). doi:10.1108/13595471311315119
45. Gerhardt, P.F., Lainer, I.: Addressing the needs of adolescents and adults with autism: a crisis on the horizon. J. Contemp. Psychother. **41**, 37–45 (2011). doi:10.1007/s10879-010-9160-2
46. Israel Ministry of Health: Evaluation of Children in the Autism Spectrum. Israel Ministry of Health, Jerusalem (2013). Retrieved from https://www.health.gov.il/hozer/mk15_2013.pdf
47. Noyman, R.: The characteristics, meanings and implications of couples relationships from the perspective of people with intellectual disability living as couples: a comparison of quality of life and self-esteem in couple's relationships versus relationships between friends. Doctoral dissertation, University of Haifa, Haifa, Israel (2013)
48. Moin, V., Duvdevany, I., Mazor, D.: Sexual identity, body image and life satisfaction among women with and without physical disability. Sex. Disabil. **27**, 83–95 (2009). doi:10.1007/s11195-009-9112-5
49. Byers, E.S., Nichols, S., Voyer, S.D., Reilly, G.: Sexual well-being of a community sample of high-functioning adults on the autism spectrum who have been in a romantic relationship. Autism **17**, 418–433 (2013). doi:10.1177/1362361311431950