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The Effect of Gender of Child with Autism Spectrum Disorder on Maternal Distress, Guilt
and Quality of Life

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DEDICATION

I would like to dedicate this thesis to my husband and daughter, whose love and care have kept me going.

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Abstract

The present study examined the effect of gender of child with Autism Spectrum Disorder (ASD) on (i) maternal distress, (ii) guilt, and (iii) quality of life (QoL). A purposeful sample of 132 mothers, divided between mothers of children with autism (N=44), mothers of children with learning disabilities (N=43) and mothers of typically developing children (N=44) participated in the study. The participants filled in the Parental Stress Index- Short Form (PSI-SF), WHOQOL-BREF to measure maternal quality of life, and the Maternal Guilt Questionnaire. In terms of the results, contrary to the proposed hypothesis, mothers of females with autism reported higher distress than mothers of males with autism. In addition, gender had no effect on maternal guilt nor on maternal quality of life. However, mothers of children with autism reported higher distress than mothers of children with learning disabilities, who further displayed higher distress than those of typically developing children. The results were explained in terms of cultural and stereotypical attitudes and norms.

Effect of Gender of Child with Autism Spectrum Disorder on Maternal Distress, Guilt, and Quality of Life

The prevalence of Autism Spectrum Disorder (ASD) has been increasing within the past few years worldwide (Matson & Kozlowski, 2011), affecting boys four to five times more than girls (Lai, Lombardo, Auyeung, Chakrabarti & Baron-Cohen, 2015). Following the receipt of ASD diagnosis, stressful feelings are often raised in the parents of the diagnosed child (Banach, Iudice, Conway, & Couse, 2010). However, the long-term adjustment process tends to be manifested differently in mothers and fathers of children with ASD (Jones, Totsika, Hastings, & Petalas, 2013). Since mothers are the primary caregivers of children with special needs (Rodrigue, Morgan & Geffken, 1992), the present study will be the first of its kind, in which the relationship between the gender of children with ASD relative to maternal distress, guilt and family quality of life will be addressed in Beirut, Lebanon.

Numerous studies have focused on parental differences, family support and internal stresses that accompany raising a child with ASD. Nevertheless, there remains a gap in research relating the gender of children with ASD to their parents' emotional experiences. Of the very few studies that tackled this variable, one study in the west revealed that when the diagnosed child is a female, parental distress tends to be higher than when it is a male (Zamora, Harley, Green, Smith, & Kipke, 2014). However, would that be the case too in the Arab world where son-preference is dominant? The importance of shedding light on this aspect comes as a result of the cultural trait that dictates the importance of giving birth to a typically developing (healthy) male offspring in the Arab world (Fuse, 2010).

Parents often strive to offer their children the maximum they can and to raise them in the best way possible. However, feelings of guilt often accompany most parents of children with ASD in comparison to parents of non-autistic children (Sivberg, 2002); in which parents feel that they “caused” their children’s disability or are simply “not doing enough” for them (Gorski, 2013). These burdening feelings take place regardless of the child’s gender. Given the significance of raising a male offspring in the Arab world (Fuse, 2010), and the social pressures it places on the mother, it is crucial to address whether levels of guilt would differ in Lebanese mothers of children with ASD based on the diagnosed child’s gender or not.

A son in an Arab family is extremely important as he brings more happiness than the birth of girls due to various “economical, social or psychological benefits” (Harahsheh, 2011). Thus one can deduce that Quality of Life (QoL), defined as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization (WHO), 1996, p. 5), would be higher when a son is born rather than a daughter in Arab families. Nevertheless, would the case still be as such when the child born has ASD?

It is crucial to keep in mind that many challenges are often faced by family members upon interacting with a child with disability (Brown, Mac-Adam, Wang, & Iarocci, 2002) in comparison to a typically developing child. Family dynamics as a whole are usually affected by the diagnosis (Koydemir & Tosun, 2009), especially the primary caregivers, whose life could be significantly impacted (Dardas & Ahmad, 2014). Autism is not a disorder that one can simply be “cured” from; on the contrary, it persists throughout

one's lifetime requiring care and attention (Magana & Smith, 2006). Thus combining both factors together: the birth of a male offspring and ASD, would the maternal QoL be different in Lebanese families when it is a boy with ASD rather than a girl?

Background of the Study

Gender of Child with ASD and Parental Distress

Conflicting results were found in the few studies carried out tackling the effect of gender. In one study, upon evaluating how the gender of children with ASD and access to treatment relates to parental stress, a heightened level of distress as well as parent-child dysfunctional interaction was found in mothers of girls in comparison to boys (Zamora et al., 2014). In addition, reduced access to services played an active role in elevating parental stress in mothers of girls, but not boys, with ASD. However, inconsistent findings were found with an earlier research that had also focused on the determinants behind psychological distress in mothers of children with Pervasive Developmental Disorder (PDD)- a form of autism (Tobing, & Glenwick 2006), where maternal distress was not found to be related to gender of the child.

In the realm of the present study, given that there are cultural differences that distinguish the west from the east, especially that certain “stressors are culture-specific” (Laungani, 1992), this study can provide fruitful statistics upon further exploring whether maternal distress in Lebanese mothers of children with ASD can be extenuated due to gender. Because of the “socially ascribed relative value of women/girls and men/boys as persons” in Lebanon, which is clearly evident in son-preference amongst Lebanese families (Khalidi, A., Nahhas, N., & Nuwayhid, I., 2004), it is expected that raising a boy with ASD would be correlated with higher maternal distress than raising a girl with ASD.

Autism and Guilt

Little is known about maternal guilt in raising a child with ASD. Most of what is found appears primarily in non-scientific research, such as blogs of mothers discussing their feelings of guilt in relation to their child's diagnosis. For example, mothers often share how they feel they could have done something to "stop" their child's autism (Gobski, 2013). Of the few systematic studies carried out, Kuhn and Carter (2006) examined the associations between maternal self-efficacy, defined as "feelings of competence in the caretaking role" of children with ASD and their parenting perceptions, including guilt. Data revealed that 80% of the mothers reported feelings of guilt over "not doing as much as they should be" for their child with autism. A significant negative correlation between maternal self-efficacy and guilt was revealed.

With reference to autism and maternal guilt, no mention of the children's gender and maternal guilt towards it was made in the literature found, which is important in terms of our study. In the scope of the present study, based on the importance of male offspring in the Lebanese community, one can speculate that maternal guilt towards boys with ASD would be higher than maternal guilt towards girls with ASD.

Autism and Family Quality of Life

Based on the recent findings by Dardas and Ahmad (2014), it seems that regardless of the cultural background, raising a child with ASD affects the family quality of life from the parent's perspectives. However, the extent up to which it affects them depends on a number of factors, including "their stress levels, coping strategies, demographical characteristics and cultural context." Nonetheless, since no mention has been made of a specific gender effect on family QoL, the present study will go a step further in specifically

targeting this variable to see whether raising a female or male with ASD can play a role in amplifying or diminishing maternal family QoL in an Arab culture.

Statement of the Problem

The main aim of the present study was to identify the relation between gender of children with ASD relative to maternal distress, guilt and family quality of life. Up to our knowledge, no similar research had been carried out on these 3 variables, neither in the west nor the Arab world. And unlike the previously mentioned studies, in the realm of the present study, three groups were recruited: a group of mothers with a child with ASD, another raising a child with LD, and a third comparative group raising a typically developing child. The reason for these three groups was mainly to help ensure that the results would be due to the variable in question, in this case ASD, and not attributed to having a disorder or any other reason.

In terms of maternal distress and gender of child with ASD, unlike the studies mentioned earlier, it was predicted that in Lebanon, where an Arab culture prevails,

H1: Mothers of boys with ASD experience higher distress than mothers of girls with ASD.

With reference to maternal guilt and autism, the literature targeted the variable in different ways, thus revealing diverse findings. In one study high feelings of guilt were found to correlate with raising a child with ASD, whilst in another, guilt was centered around the typically developing child. Because of the son preference phenomenon in the Arab world, it was hypothesized that:

H2: Mothers of boys with ASD endure higher levels of guilt than mothers of girls with ASD.

As for family QoL, the literature revealed consistent findings of poor QoL in mothers raising children with ASD, with no mention to the child's gender. Again, given the importance of having a male offspring in the Arab world, and how families are usually happier with the birth of boys rather than girls, it was predicted that

H3: Mothers of girls with ASD experience lower QoL than mothers of boys with ASD

In line with the previously mentioned literature stating that it is more distressing for a mother to raise a child ASD than one with LD, it was expected that in this study too

H4: Mothers of children with LD experience lower distress than mothers of children with ASD.

H5: Mothers of children with ASD have a lower QoL than mothers of children with LD

And finally, since mothers of typically developing children do not have to undergo any of the stressors mentioned related to their child's development, it was hypothesized that

H6: Mothers of children with LDs have a lower QoL than mothers of typically developing children.

Furthermore, since previous studies have examined between groups comparisons (ASD, LD and normative children), and the interaction of family quality of life and parental distress separately with ASD and LD, the current study went a step further: It provided us with the opportunity to examine the interplay of all these variables taken together and which correlated more strongly with the child's gender.

Significance of the Study

It was crucial to study whether gender does play a role in maternal feelings of guilt, distress and family quality of life in parenting children with autism for various reasons. First of all, no study in the Arab world nor the West had addressed these variables at once.

Second, the cultural effect –namely son preference- and whether it affects parenting children with autism, was worth exploring, especially because of the implications it could have on the families raising these children. Third, the results could help by providing insight and further understanding to the state of the mothers raising them. And last but not least, the clinical impact the results would leave on therapeutic measures are important, as they would assist the parents of children with ASD cope with the stressors of raising their child.

Overview of Methodology

A convenient sample of 132 Lebanese mothers of children under the age of 12 with ASD, LD, and TD was recruited through health centers, nurseries and schools around Lebanon. They were asked to fill in the survey with utmost confidentiality. The questionnaire was in English and included a few demographic questions followed by the following scales: Parenting Stress Index 3, short-form (PSI-SF) used to assess for maternal distress; the Maternal Guilt Questionnaire to assess maternal guilt, and the World Health Organization Quality of Life Assessment-BREF self-administered instrument (WHOQOL-BREF) was used to measure maternal quality of life. Data from the surveys was analyzed using the independent t-test and one-way analysis of variance (ANOVA).

Definition of Key Terms

Autism: a complex childhood developmental disorder affecting boys four times as much as girls and negatively impacting the child’s “intellectual, social, and linguistic abilities” (American Psychiatric Association (APA), 2000).

Distress: “Unpleasant feelings or emotions that impact ones level of functioning” (Williams, 2011).

Guilt: Difficult feelings where mothers feel that they are “not doing enough to promote their child’s development” (Kuhn& Carter, 2006).

Quality of Life: “individuals’ perceptions of their positions in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (p.5)

Chapter 2

Literature Review

Starting with the importance of having a male offspring in the Arab world, it is essential to state a few facts with that regard. Upon marriage, a lot of societal and family pressures are placed on the woman, who is expected to bear children within no time. Males are the preferable offspring gender and sympathetic feelings are often drawn towards a wife without a male child (Collelo, 2003). Be it through the feasts and festivities that take place upon the birth of a male child, or through the ‘naming’ where the first male offspring usually takes up the name of his grandfather; it always goes without saying that male children are the preferred ones in the family and are “given special privileges” (Collelo 2003) in comparison to the birth of females.

At birth, one cannot tell if a child has autism or not. Autism is first diagnosed at around 18 months of age, when the child starts to show repetitive and stereotypical behaviors and fails to show social interests in others. Raising a child with autism spectrum disorder places high demands on the family’s primary caregivers, especially since ASD is not a disorder that resolves away with time, instead continues throughout adulthood and one’s lifetime. Furthermore, parents are more likely to undergo negative psychological experiences upon caring for their child with ASD (Zamora et al., 2014).

Even though autism affects boys four times as much as girls, yet there is also a difference in the way the disorder manifests itself in each gender (Amr, Raddad, El-Mehesh, Mahmoud, & El-Gilany, 2011), where specific symptoms tend to be more dominant in one gender but not in the other. Taking together the importance of raising a typically developing, male offspring in the Arab world (Fuse, 2010), in addition to the

maternal distress that mothers undergo upon caring for their child, there still remains the question whether gender of the child with ASD will impact the distress level felt by mothers of children with ASD.

Mothers are more vulnerable than their partners when it comes to raising a child with ASD (Shtayermman, 2013). Upon receipt of the diagnosis, many mothers of children with ASD undergo a huge interplay of negative experiences that include holding themselves responsible for their child's disorder (Kuhn & Alice, 2006). However, there has been a failure in the literature to address whether feelings of guilt are more pronounced in mothers of boys in comparison to girls with ASD.

Not only does the diagnosis arouse feelings of guilt in mothers (Kuhn & Alice, 2006), but it also brings about major changes and turbulences to the family subtleties as a whole, where difficulties and nuances are often faced upon adapting to the new life changes (Martins, Bonito, Andrade, Albuquerque, & Chaves, 2014). Thus, the quality of life of all members involved is altered. Nevertheless, it is unknown whether gender of child with ASD plays a significant role in affecting maternal quality of life in Arab families, where male offspring are more favorable and carry the family legacy and name. This study aims to tackle the relationship between the gender of children with ASD relative to maternal distress, guilt and maternal quality of life.

Autism and Parental Distress

As expected, stress levels are more prominent in mothers of children with ASD compared to mothers of typically developing children (Foody, James, & Leader, 2015). However, it is surprising to learn that different types of developmental disorders affect mothers differently, in which mothers of children with ASD experience higher stress than

those whose children have learning disabilities (LD) (Blacher and McIntyre 2006). Nevertheless, very few studies sought to further analyze the results to assess whether the gender of the affected child affects the mother in any particular way.

On the other hand, it has also been revealed that gender of the child with ASD affects stress levels in fathers too and not only mothers (Rivard, Terroux, Parent-Boursier, & Mercier, 2014). Researchers in this study used the feedback of mothers and fathers to reveal factors contributing to stress in parents of children with ASD. Gender of child was found to be a stress predictor in particularly fathers of children with ASD and not mothers. Fathers, in comparison to mothers, scored lower on the Parent-Child Dysfunctional interaction scale, which was mainly used to assess how the parents perceived the bond they have with their child.

In a study by Zamora et al. (2014), the researchers were interested in evaluating how the gender of children with ASD and access to treatment relates to parental stress. Mothers of 27 girls and 89 boys were asked to complete self-reported surveys. Even though both genders shared similar autism features, the results revealed heightened parental distress and parent-child dysfunctional interaction in mothers of girls in comparison to boys. Furthermore, reduced access to services played an active role in elevating parental stress in mothers of girls, but not boys, with ASD.

Another study that attempted to compare parenting stress and closeness between mothers of children with ASD and TD children, again in California and using the parenting stress index, showed in alignment with their hypothesis, higher stress levels within mothers of children with ASD in comparison to those raising TD children (Hoffman, Sweeney, Hodge, Lopez-Wagner & Looney, 2015). However, in terms of gender, conflicting results

to those found by Zamoorah et al. (2014) the year before were found: no gender differences were noted between raising a male to female in the group of children with autism.

Even though not one of their main hypotheses, yet one of the results found by Batool & Khurshid (2015) on effect of gender on parental distress came consistent with the results mentioned earlier by Hoffman et al. (2015). Gender was not one of the factors that led to higher stress levels in either parent of children with disability. On the contrary, it was found to play no role whatsoever. Instead, levels of maternal stress were linked to severity of impairment as well as self-efficacy (Batool & Khurshid, 2015).

Another one of the few researches carried out in a non-English speaking country, was by Samadi and McConkey (2014) who studied the impact on Iranian mothers and fathers of raising a child with autism. Based on the results of the 103 parents who filled in the PSI, mothers scored remarkably higher than fathers on “measures of stress and emotional well-being” (Samadi & McConkey, 2014). However, no mention to the effect (if any) of child’s gender on either parent was made.

From a broader perspective, it is clear that to date there are conflicting findings, with those present, relating the gender effect of children with ASD to maternal distress, even though all the mentioned studies were conducted in the west. As a result of that, one cannot be sure whether their findings, or which findings, can be generalized to the Arab world.

Autism and Guilt

Literature is scarce on autism, guilt and gender taken together. Nevertheless, a consensus has been reached with regards to the repeated feelings of guilt mothers feel towards their children with autism. Guilt is known to fall under the “difficult emotions”

mothers of children with ASD experience upon raising their child (Myers, Mackintosh, & Goin-Kochel, 2009).

One of the very few studies that tackled maternal guilt and autism was by Kuhn & Carter (2006), where 170 mothers completed surveys on maternal self-efficacy. Of the participants that filled in the data, the majority felt that they are not doing “as much as they should be” for their child with autism.

Interestingly, another study went a step further in which it not only targeted the experiences and perceptions of mothers towards their child with ASD, but also towards their other typically developing (TD) child (Meirsschaut, Roeyers, & Warreyn, 2010). Contrary to their hypothesized relationship, maternal guilt was centered more around the TD child and not the child with autism, where mothers believed “they were not doing enough” for their typically developing child. This study is a very similar to the one we will be carrying out. However, it was a within group comparison where mothers feelings towards both their children was assessed. In terms of our study, it will focus on between groups in which comparisons between feelings of mothers raising a typically developing child, another group raising a child with autism and a third one raising a child with a learning disability will be compared.

Autism and Quality of Life

To date, possibly only one study in the Arab world has specifically examined family quality of life (QoL) in parents of children with ASD, which includes “functioning across various health domains and parent’s adaptation to their child’s disability” (Dardas & Ahmad, 2014). In this study, where both parents filled out questionnaires, no significant differences in QoL were reported between mothers and fathers. However, an overall poor

QoL was identified amongst those parents of children with ASD for uncertain reasons that maybe related to raising the child or external factors the parents maybe experiencing. Nevertheless, it is also worth mentioning that this study contained no control group, instead the mean scores were compared to previous research that used the same measure, the WHOQOL-BREF (discussed in the coming sections).

In comparison between 3 family groups: one with a child with autism, another with a child with Down's syndrome and a third with a typically developing child; differences were noticeable in family quality of life (Brown et al., 2006). A total of 69 participants filled in the Family Quality of Life Survey in which its results demonstrated differences between the 3 groups. Satisfaction was highest in the family of a typically developing child; next came in the families with a child with Down's syndrome, whilst the families with the lowest quality of life score were those with a child with autism. No further analysis to the gender of the children was made.

Inconsistent findings were found in a partially congruent study carried out in Taiwan (Yamada, Kato, Suzuki, Suzuki, Watanabe, Akechi, & Furukawa, 2012), where 333 participants filled in the Beach Center Scale to assess for family quality of life in families of children with intellectual disabilities and autism. Unlike the previously mentioned study, no statistical differences were found across both mentioned families.

Even though differences between parents with respect to raising children with autism and other disabilities have been addressed, yet none of the mentioned studies attempted to test for whether the child's gender with ASD affected maternal QoL or not. It is crucial to investigate this variable especially that the whole family dynamics could

change and be affected once the much-awaited male offspring is diagnosed. Hence, based on the above-discussed review of literature, the following hypotheses were investigated:

- 1) Mothers of boys with ASD experience higher distress than mothers of girls with ASD.
- 2) Mothers of boys with ASD endure higher levels of guilt than mothers of girls with ASD.
- 3) Mothers of girls with ASD experience lower QoL than mothers of boys with ASD.
- 4) Mothers of children with LD experience lower distress than mothers of children with ASD.
- 5) Mothers of children with ASD have a lower QoL than mothers of children with LD.
- 6) Mothers of children with LD have a lower QoL than mothers of typically developing children.

CHAPTER 3

Method

Participants

The purposive sample chosen consisted of 132 Lebanese, females aged between 25 and 46, with an average age group of 34 years old, able to easily read and write English. Out of the participants, 32 were mothers of boys with autism aged between 2 and 12; 13 were mothers of girls with autism aged between 2 and 12; 29 were mothers of boys with learning disabilities aged between 7 and 12, 14 were mothers of girls with learning disabilities, and 30 were mothers of single, typically developing boys aged between 2 and 12, and 14 were mothers of single, typically developing girls aged between 2 and 12.

Materials

After oral consent was given from behalf of the participants, the following demographic questions such as maternal age, number of offspring, and age and gender of the child in question were added to the questionnaire found in Appendix A, which they were asked to fill in.

Parenting Stress Index 3, Short Form

The Parenting Stress Index-short Form (PSI-SF) found in Appendix B, was used to assess for maternal distress throughout the 3 groups of participants. The short form is a 36-item subset of the original 120-item full-length scale, with 3 sub-scales, 12 questions for each of Parental Distress (PD); Parent-Child Dysfunctional Interaction (PCDI); and Difficult Child (DC). Examples of the questions of each sub-scale include for PD: “Having a child has caused more problems than I expected in my relationship with my spouse”, for

PCDI: “My child rarely does things for me that make me feel good”, and for DC: “I feel that my child is very moody and easily upset”.

This PSI-SF is applicable for parents of children from 0 to 12 years (Zamora et al., 2014) in which the items are scored using a 5-point Likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree) (Dardas & Ahmad, 2014). Based on the recommendation of Dardas and Ahmad (2014), the valid and reliable index with 30 items instead of 36 was used with parents of children with ASD, LD and TD in the Arab world. No additional modifications were made.

Maternal Guilt Questionnaire

Due to the shortage of methodical studies and available questionnaires addressing guilt in mothers of children with ASD, Kuhn and Carter (2006) rationally derived a questionnaire, of which construct validity and reliability were assured. The survey, Maternal Guilt Questionnaire (Appendix C), is made up of 4 questions; however, in order to proceed after the first one, mothers should have answered “yes” to the first question which asks “do you ever feel responsible or guilty because you believe you are not doing as much for your child with autism as you think you should be doing”. Next they were asked to fill in the frequency of such feelings, (e.g. “everyday or almost everyday”) on a 5-point scale, and mark the situations of where they occur (e.g. “family gatherings”; “after I had a conflict with my partner or family member”).

The same questions, with minor modifications, were used in Meirsschaut et al. study (2010) for mothers assessing their guilt feelings towards their typically developing children. In our study, the same set of questions were used for the other 2 groups of

mothers with modifications that included removal of the term “autism” from the questions. (Meirsschaut, Roeyers & Warreyn, 2010)

WHOQOL-BREF

The WHOQOL-BREF Field Trial Version (Appendix D) is a short form, 26-item scale of the original 100-questions (WHOQOL-100) assessment that measures Quality of Life (WHOQOL-BREF). This instrument is made up of 4 domains: physical health, psychological, social relationships, and environment, in addition to two separate items “Overall quality of life” and “General Health”. It includes demographics, such as gender and date of birth, followed by a series of questions whereby the participants had to rate their answers along a 5-point Likert scale ranging from either “very poor” to “very good”, “very dissatisfied” to “very satisfied”, “not at all” to “an extreme amount” and “never” to “always”, depending on the question and choices available. The same questionnaire was used with all 3 groups without any amendments.

Procedure

Participants in this study consisted of females only, who could read and write English, and were chosen based on a purposive sampling and willingness to complete the survey either online or on paper. All participants gave in their oral consent and utmost confidentiality and anonymity was ensured. The demographic questions added included maternal age, child’s gender and age, as well as the total number of children in the family.

Before proceeding with the data collection, a pilot study on a sample of 42 participants was carried out to ensure reliability of the scales chosen. High internal reliabilities were found for both the PSI-SF and WHOQOL-BREF scales and their sub-scales used. However, internal reliability was not calculated for the Maternal Guilt

Questionnaire because of the differences between the questions and the scoring of each, based on the recommendations by Kuhn and Carter (2006).

Data collection took place during the period between September 2017 and December 2017, after which it was entered into SPSS. For data analysis, an independent t-test was used to measure the within group differences of gender, followed by planned comparisons when needed. However, for between groups comparisons, one-way analysis of variance (ANOVA) was used, and further post-hoc analysis, mainly Tukey, was used for further analysis.

CHAPTER 4

Results

Reliability Testing

To determine the internal consistency of the PSI-SF and the WHOQOL-BREF used, Cronbach's alpha was calculated for both the scales and sub-scales. However, reliability analyses were not calculated for The Maternal Guilt Questionnaire because it only asks about the occurrence, frequency and circumstances of guilt. The table below displays the current as well as previously calculated reliability coefficients for the other two scales.

Table 1

Cronbach's Alpha for the PSI-SF and WHOQOL-BREF scales

Scale/Subscale	Previous Cronbach's alpha	Current Cronbach's alpha
PSI-SF		
PD	.91	.86
PCDI	.86	.79
DC	.87	.86
Total Scale	.91 – .92	.91
WHOQOL-BREF		
Physical Health	.86	.78
Psychological Health	.84	.80
Social relationships	.67	.73
Environment	.82	.85
Total	.91 – .93	.89

Hypothesis Testing

Hypothesis 1 Mothers of boys with ASD experience higher distress than mothers of girls with ASD.

When comparing the distress levels reported by mothers of males to mothers of females with autism, no high significance ($p = 0.09$) was seen (table 3). However, on basis of a planned comparison between both genders (females and males) with respect to maternal distress, the results analyzed were significant ($p = 0.05$) but opposing to the proposed hypothesis. Distress was found to be higher in mothers raising females with autism than it is in raising males with autism (table 3).

Table 2

Means of Maternal Distress

	ASD	LD	TD	Total Means
Males	88.84	75.97	69.4	78.33
Females	99.69	83.57	69.71	83.95

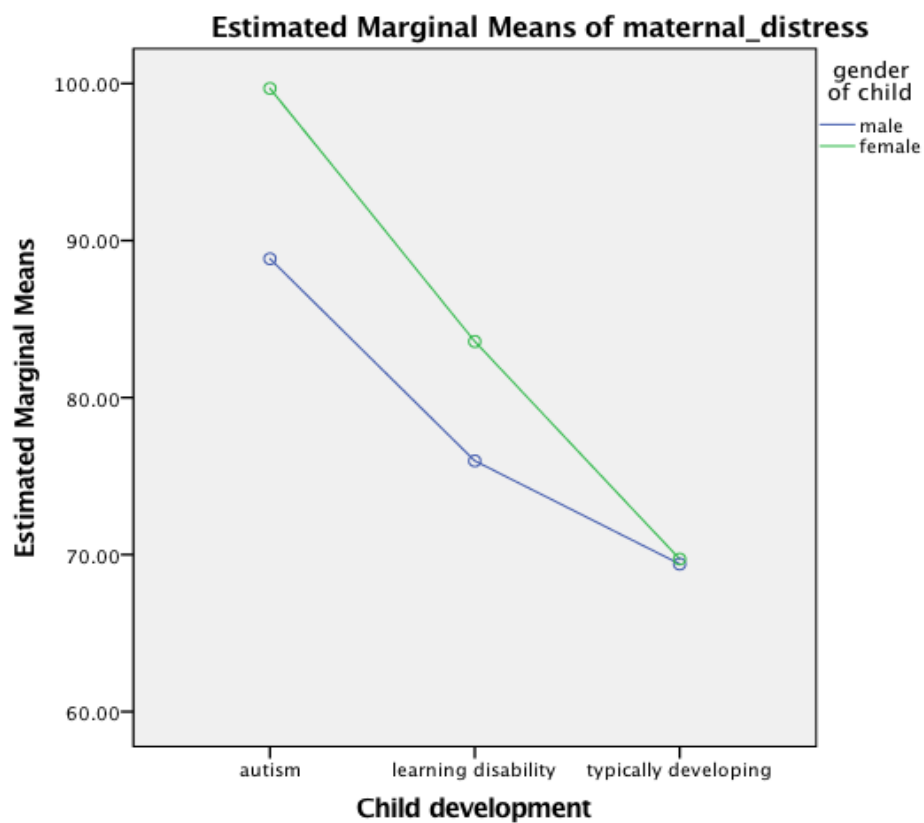
Table 3

Independent Samples t-test between genders of children with ASD

Variable	Sig.
Maternal Distress	0.091
Maternal Guilt	0.190
Maternal QoL	0.355

Table 4*Planned comparison of Maternal Distress*

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Child Gender	1104.815	1	1104.815	3.840	0.052
Child Dev.	11565.899	2	5782.950	20.100	0.000
Child Gen* child dev.	549.097	2	274.548	0.954	0.388

Figure 1*Maternal Distress in mothers of children with ASD.*

Hypothesis 2 Mothers of boys with ASD feel higher levels of guilt than mothers of girls with ASD.

With respect to guilt, again no significance ($p = 0.19$) was found in mothers between raising a boy with ASD in comparison to raising a girl with ASD. Furthermore, upon conducting a planned comparison between both, no significant results were found (table 5).

Table 5
Means of Maternal Guilt

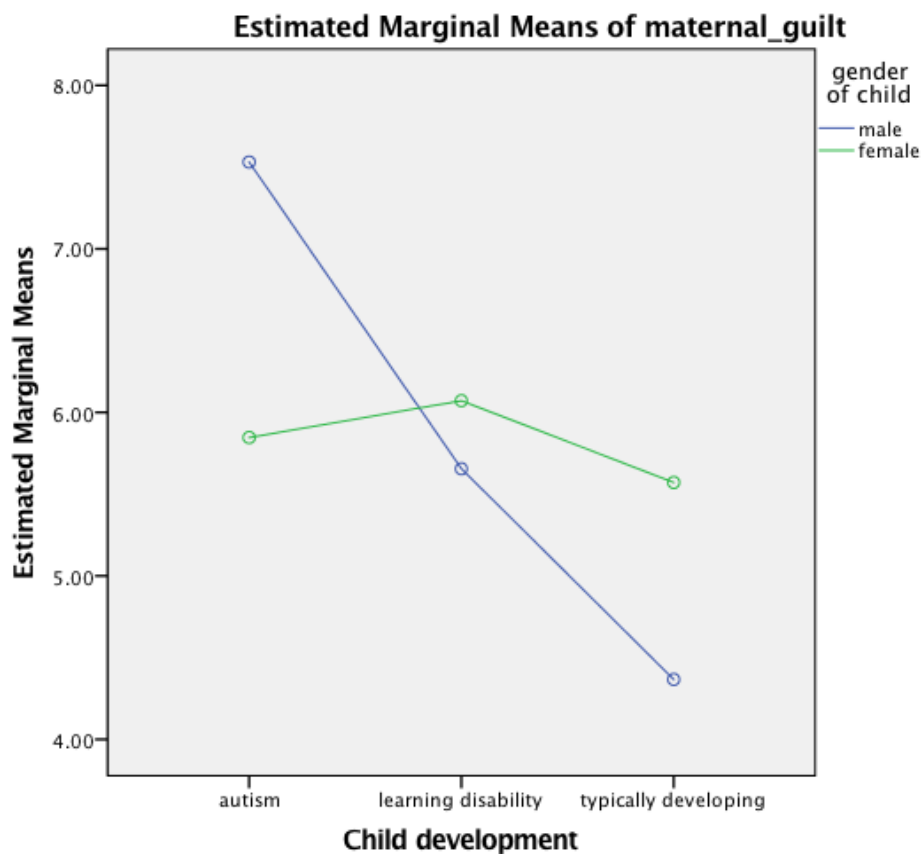
	ASD	LD	TD
Males	7.53	5.66	4.47
Females	5.85	6.07	5.57

Table 6
Planned comparison of Maternal Guilt

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	159.274	5	31.855	3.414	0.006
Intercept	3851.225	1	3851.225	412.794	0.000
Child Gender	0.013	1	0.013	0.001	0.970
Child Dev.	55.610	2	27.805	2.980	0.054
ChildGen*child dev	41.740	2	20.870	2.237	0.111

Error	1175.537	126	9.330
Total	5885.000	132	

Figure 2 Maternal Guilt in mothers of children with ASD.



Hypothesis 3 Mothers of girls with ASD experience lower QoL than mothers of boys with ASD.

Based on the results of comparing maternal QoL upon raising a female in comparison to a male, no significance was found between both variables ($p = 0.49$). Planned comparisons showed no significant results either ($p = 0.405$).

Table 7*Means of Maternal Quality of Life*

	ASD	LD	TD
Males	83.47	89.48	91.57
Females	86.92	89.78	86.86

Table 8*Planned Comparisons of Maternal Quality of Life*

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	1180.429	5	236.086	1.347	.249
Intercept	874630.869	1	874630.869	4991.197	.000
Child Gender	447.533	2	233.767	1.277	.282
Child Dev.	2.844	1	2.844	.016	.899
ChildGen*child dev	319.232	2	159.616	.911	.405
Error	22079.571	126	175.235		
Total	1045468.00	132			
Corrected Total	23260.000	131			

Hypothesis 4 Mothers of children with LD experience lower distress than mothers of children with ASD.

Based on the results analysis using one-way ANOVA, significant differences ($p = 0.00$) were found between the groups. Further planned comparisons using “post-hoc” were carried out, in which significant results were also found ($p = 0.043$).

Table 9

One-way analysis of variances between groups

Variable		Sig.
Maternal Distress	Between groups	0.000
Maternal Guilt	Between groups	0.003
Maternal QoL	Between groups	0.089

Table 10

Post-hoc analysis (Tukey) in Maternal Guilt

Variable	Child Development	Sig.
ASD	LD	0.139
ASD	TD	0.002
LD	TD	0.258

Hypothesis 5 Mothers of children with ASD have a lower QoL than mothers of children with LD.

Through the post-hoc analysis, no significant differences were found between the QoL of mothers with ASD in comparison to LD ($p = 0.128$).

Hypothesis 6 Mothers of children with LD have a lower QoL than mothers of typically developing children.

Based on the results followed by the post-hoc analysis, no significant differences were found between mothers of children with LD and typically developing children in terms of QoL ($p = 0.999$).

Chapter 5

Discussion

To our knowledge, the current study is the first to investigate the effect of gender of child with autism spectrum disorder on maternal distress, guilt and quality of life in Beirut, Lebanon and the Arab world. The main focus was on mothers, knowing that they are the main caregivers in children with special needs (Rodrigue et al., 1992).

Through the research, it was hypothesized that mothers of boys with ASD experience higher distress than mothers of girls with autism. However, based on the analysis of results, a weak relationship was found between mothers of boys with autism and maternal level of distress. Nevertheless, upon pursuing further analysis, higher distress was evident in mothers of girls with ASD rather than boys. These results came in accordance with a previously carried out research in the west, where mothers of girls with ASD had reported significantly higher distress than mothers of boys (Zamora et al., 2014).

Thinking away from the importance of raising a male in the Arab world, a number of factors could attribute for the higher distress found in mothers of girls with autism in comparison to mothers of boys. First, many girls face the difficulties of “fitting in” (Cridland, Jone, Caputi & Magee, 2014) which can be a huge source of worry to their mothers. That is, at school, children with ASD usually have difficulties pursuing academics in the mainstream classrooms and most of the times receive special education services known as “pull-out sessions” or “small group classrooms”. However, since boys with autism outnumber girls on the spectrum by a ratio of 4 to 1, usually most of the “small group” classrooms are comprised of boys rather than girls. Here, this imposes a problem for girls with ASD who not only now have difficulties reaching out to other students in their

mainstream classrooms, but are also a minority in their “small group” classes (Cridland et al., 2014).

Another concern that may elevate levels of distress in mothers of girls in comparison to boys with ASD is puberty. “Onset of menstruation is by far the greatest puberty-related concern for mothers of girls with autism” (Cridland et al., 2014).

Explaining to girls on the spectrum about private matters, bodily changes as well as adolescence can be really difficult. In addition, with age, hygiene demands increase too and mothers need to be involved a lot more with their daughters especially when it comes to helping them adjust to the changes (Cridland et al., 2014). Achieving this turning point can be highly stressful and worrisome to mothers, though sometimes once it has been achieved, mothers tend to learn that it was not as stressful as they had imagined it to be (Cridland et al., 2014).

The issue of marriage may be one of the most significant worries of mothers of girls with ASD in the Arab world. “In Arab culture, marriage is a well-defined turning point that bestows prestige, recognition, and societal approval on both partners, particularly the bride” (Rashad, Osman, & Roudi-Fahimi 2005). Women are expected to reproduce in Arab societies, where their status is mainly defined by their primary roles as mothers and wives. “By “failing” to meet these expectations, single women do not have an easily defined or comfortable niche in society. Single women with no education or job skills face particular problems in the Arab world because of their lack of financial independence” Rashad et al. (2005). Females with autism do not easily form social relationships, and very few are those who are able to live independently, work and get married (Howlin, 2000). Thus, worrying

about their daughter's 'future' and how the society expects specific outcomes of them, tends to be a source of worry to mothers of girls with ASD.

With respect to maternal guilt, no differences were seen between raising a female in comparison to a male with ASD. The study showed that mothers with children with ASD are ridden with remorseful feelings regardless of their offspring's gender. However, based on figure 2, even though no significant the measures of guilt between both genders were prevalent, yet guilt was more pronounced in mothers of boys with autism than in mothers of girls with ASD. A possible explanation for that could go back to the different behaviors exhibited in boys versus girls with autism. Autistic girls exhibit less repetitive and stereotypical behaviors than boys do and they tend to engage in activities similar to those of typically developing children, such as 'pretend-play' (Frazier, Georgiades, Bishop, & Hardan, 2014). On the other hand, boys with ASD tend to present more stereotypical behaviors than girls (Frazier et al., 2014), which could also imply more intervention needed and mothers feeling that they need to do more for their child.

To give a general overview of guilt feelings that often arise in mothers of children with ASD can be supported by a case study carried out by Benedix and his colleagues in 2007. A group of families, who were unable to provide well for their children with ASD, had to move them to a group home. Even when they saw their child's improvement a couple of years later, they still went through an ethical dilemma that brought about feelings of guilt (Benderix, Nordstrom, & Sivberg, 2007). No matter what mothers do, they will always feel guilty and that what they are doing is not enough for their child with ASD and that they could always do more, regardless of the child's gender.

When examining maternal quality of life, mothers of girls with ASD did not report a lower QoL than mothers of boys with ASD. In addition, further analysis, including planned comparisons, also showed no significant differences between both genders. Of the various possible explanations, confounding variables are likely such as the level of autism severity in each group. Interestingly, research has also shown that a positive mother/child with autism relationship translates into better psychological well-being, and optimism plays a pivotal role in mental and physical health (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004). Thus, it is also possible that different cognitions and optimism levels in either group affected the maternal quality of life.

Upon comparing distress levels amongst mothers of children with learning disabilities and mothers of children with ASD, distress was found to be higher in the latter group. Even though both autism and learning difficulties are developmental delays, yet the way each disorder manifests itself is different. Raising a child with autism is a lot more demanding than raising a child with learning difficulties. Autism affects social interactions, academics, relationships, as well as behaviors; whilst learning disabilities on the other hand are basically centered around academics mainly.

Through further analysis, and mainly planned comparisons, not only was maternal distress found to be higher in mothers of children with autism than it is in mothers of children with learning difficulties; nevertheless, the latter was also found to be higher than that in mothers raising typically developing children. Thus, the presence of a disorder of any sort tends to affect maternal distress, and the more severe the disorder, the higher the maternal distress is.

Unlike distress, based on the results analysis, maternal quality of life was not significantly linked to the disorder in question. Mothers of children with ASD did not show a significantly lower quality of life in comparison to those with learning disabilities. However, this was inconsistent with the literature, which had clearly stated that the more severe the child's disability was, the poorer the parent's quality of life (Leug & Tsang, 2003). Further analysis to assess whether maternal age may have played a role in the quality of life of both groups also showed no significant differences. However, a possible explanation regarding the conflicting results could be due to confounding variables such as the socioeconomic status (SES) of the parents and marital satisfaction, both of which were not taken into consideration in this study.

In a previous study conducted in Iran, both SES and marital satisfaction were strong determinants of maternal quality of life of children with ASD (Mahani, Rostami, & Nejad, 2012). Another explanation could also be attributed to autism severity, which had also shown in the literature to play role in maternal quality of life (Mahani et. al. 2012). SES, marital satisfaction and autism severity were all variables that were not taken into consideration in this study.

Furthermore, the differences in children's ages in both groups of ASD and LD could have also affected the results. The average age group of the children with autism was 4.2 years old, nearly half the average age group of the learning disabilities, which was found to be 8.53 years old. Thus, here we are talking about two different age groups, each of which has its own challenges (Edwards, 1984).

Another variable that could have played a role is the time of diagnosis. The impact of a child that has been recently diagnosed tends to be a lot sounder than a diagnosis that

has had years passed upon it (Banach et al., 2010). Time of diagnosis was not mentioned in the study. In addition, in comparison to learning disabilities, autism diagnosis tends to take place during the first 18 months of age; however, learning disabilities diagnosis usually takes place at an older age, due to the requirements of testing (Siegel, 1999).

Moreover, the group of mothers with children with learning disabilities also did not show a significantly lower quality of life in comparison to mothers of typically developing children. This was contrary to the previous literature that had demonstrated a lower maternal quality of life in families of children with learning disabilities in comparison to typically developing children (Walden, Pistrang & Joyce, 2000). Further analysis using the maternal age and Pearson correlation, showed no significant differences between both groups on maternal quality of life. Again, this could also have been due to confounding variables such as the family's socioeconomic status, which was not accounted for in this study.

Another possible reason is the age group of the children, in which the mean ages for the children with learning disabilities was 8.53 years old, in comparison to the typically developing children which was found turned out to be 3.16. The differences in the ages also refer to different stage groups at school (Edward, 1984), in which children aged 3 are usually in their preschool years, whilst those aged approximately 8 are in their primary school years.

Clinical Implications

Clinically, this study has shown that maternal distress tends to be higher in mothers of females with autism than in it is in mothers of males with ASD. These results come in highly important because they help in guiding treatment methods available to mothers of

children with autism. Learning about the gender of the affected child may help in understanding the background of where the maternal distress may originate from, and thus aid in bringing about beneficial therapeutic methods. Moreover, understanding the possible reasons behind the accounted gender differences could directly address the problem and teach mothers how to deal with it differently by providing effective approaches to help them release their worries and concerns.

In addition, this study also revealed that upon comparing mothers of children with learning disabilities to mothers of typically developing children; distress tended to be higher in the former group. Clinically, this helps provide a glimpse on the importance of learning about the status of one's children, as it could actually influence the level of stress faced by their mothers, which thereby influences the whole therapeutic approach.

Limitations and Future recommendations

The limitations of the study included the participants who were all selected from one specific area in Lebanon: Beirut, rather than covering the different areas across Lebanon. In addition, specific schools, centers and nurseries were contacted rather than all, which could have led the results to move in a specific direction.

Another limitation could be the shortness of the Maternal Guilt Questionnaire, which even though it has been used in more than one study before, yet due to the differences in its questions and its scoring methods, no study has been able to test for its internal consistency. A more extensive scale will be needed to assess for maternal guilt in the future.

Furthermore, the fact that some of the results were contrary to the perceived literature leaves space for future recommendations for studies that could help in providing

answers to many questions residing around mothers of children with developmental disabilities. For instance, it is crucial to learn whether accounting for the family's socioeconomic status background could influence the maternal quality of life when raising a child with delays. In addition, it is essential to also learn about the severity of the disorder, be it in autism or learning difficulties and to measure whether that could also influence maternal distress, guilt and quality of life.

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Appendix A
Demographics

Gender: Female / Male

Age: _____

Number of children: _____

Gender of child: Female / Male

Age of child: _____

Appendix B**Parenting Stress Index 3, Short Form (PSI-SF)**

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
I often have the feeling that I cannot handle things very well	1	2	3	4	5
I find myself giving up more of my life to meet my child's needs than I ever expected	1	2	3	4	5
I feel trapped in my responsibilities as a parent	1	2	3	4	5
Since having my child I have been unable to try new and different things	1	2	3	4	5
Since having my child I feel that I am almost never able to do things that I like to do	1	2	3	4	5
I am unhappy with the last purchase of clothing I made for myself	1	2	3	4	5
There are quite a few things that bother me about my life	1	2	3	4	5
Having a child has caused more problems than I expected in my relationship with my spouse	1	2	3	4	5
I feel alone and without friends	1	2	3	4	5
When I go to a party I usually expect not to enjoy myself	1	2	3	4	5
I am not interested in people as I	1	2	3	4	5

used to be					
I don't enjoy things as I used to	1	2	3	4	5
My child rarely does things for me that make me feel good	1	2	3	4	5
Most times I feel that my child likes me and wants to be close to me	1	2	3	4	5
My child smiles at me much less than I expected	1	2	3	4	5
When I do things for my child, I get the feeling that my efforts are not appreciated very much	1	2	3	4	5
When playing, my child doesn't often giggle or laugh	1	2	3	4	5
My child doesn't seem to learn as much as most children	1	2	3	4	5
My child doesn't seem to smile as much as most children	1	2	3	4	5
It takes a long time and it is really hard for my child to get used to new things	1	2	3	4	5
I expected to have closer and warmer feelings for my child than I do and this bothers me	1	2	3	4	5
There are some things my child does that really bother me a lot.	1	2	3	4	5
My child generally wakes up in a bad mood	1	2	3	4	5
I feel that my child is very moody and and easily upset	1	2	3	4	5

My child does a few things that bother me a great deal	1	2	3	4	5
My child reacts very strongly when something happens that my child doesn't like	1	2	3	4	5
My child gets upset easily over the smallest thing	1	2	3	4	5
My child turned out to be more of a problem than I expected	1	2	3	4	5
My child makes more demands on me than most children	1	2	3	4	5
My child seems to cry more often than most children	1	2	3	4	5

Appendix C**Maternal Guilt Questionnaire**

1. Do you ever feel responsible or guilty because you believe that you are not doing as much for your child as you think you should be doing?

NO (If NO, Please skip to the next page)

YES (If YES, please answer 2a through 2c below.)

2a. How often do you feel this way? (Please check one.)

_____ Everyday

_____ Weekly

_____ Monthly

_____ Four to eleven times a year

_____ Less than four times a year

2b. When are you most likely to feel this way? (Check as many situations as may apply for you.)

_____ Family gatherings

_____ Family celebrations (e.g. birthdays, anniversaries, holidays)

_____ Vacations

_____ Spending time with couples who do not have children

_____ After I have had a conflict with my partner or family member

_____ When a family or friend offers me parenting advice

_____ When I am by myself

_____ When I am feeling down and blue

_____ When I am feeling overwhelmed by caring for my child (e.g. dealing with discipline, coordinating activities and services)

_____ When I am feeling angry

_____ When I see a younger, typically developing child do something that my child cannot do

2c. Do you feel that this feeling ever interferes with your ability to effectively parent your child?

Yes No

Appendix D

WHOQOL-BREF Questionnaire- Short Form

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

	Very poor	Poor	Neither poor nor good	Good	Very good
How would you rate your quality of life?	1	2	3	4	5

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

	Not at all	A little	A moderate amount	Very much	Extremely
To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
How much do you enjoy life?	1	2	3	4	5
To what extent do you feel your life to be meaningful?	1	2	3	4	5
How well are you able to	1	2	3	4	5

concentrate?					
How safe do you feel in your daily life?	1	2	3	4	5
How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

	Not at all	A little	Moderately	Mostly	Completely
Do you have enough energy for everyday life?	1	2	3	4	5
Are you able to accept your bodily appearance?	1	2	3	4	5
Have you enough money to meet your needs?	1	2	3	4	5
How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

	Very poor	Poor	Neither poor nor good	Good	Very good
How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your sleep?	1	2	3	4	5
How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
How satisfied are you with your capacity for work?	1	2	3	4	5
How satisfied are you with yourself?	1	2	3	4	5
How satisfied are you with your personal relationships?	1	2	3	4	5
How satisfied are you with your sex life?	1	2	3	4	5
How satisfied are you with the support you get from your friends?	1	2	3	4	5
How satisfied are you with the conditions of your living place?	1	2	3	4	5
How satisfied are you with your access to health services?	1	2	3	4	5
How satisfied are you	1	2	3	4	5

with your transport?					
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The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

	Never	Seldom	Quite often	Very often	Always
How often do you have negative feelings such as blue mood, despair, anxiety, and depression?	1	2	3	4	5