Effect of Counseling Sessions on Coping Strategies and Anxiety among Parents of Children with Ambiguous Genitalia

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Abstract: Ambiguous genitalia condition is often an emotionally stressful event for parents. Preparation and ongoing support through counseling sessions could be beneficial to both parents and children and would alleviate some of their shame, isolation and ineffective coping associated with intersexes conditions. The present work aimed to investigate the effect of counseling sessions on coping strategies and anxiety among parents of children with Ambiguous Genitalia. A one-group before-after Quasi-experimental design was used. This study was conducted on parent who coming with their children at pediatric surgery department of Mansoura University Pediatrics' Hospital and Private Center for Pediatric Surgery at Mansoura city. The sample included all parents which their children was diagnosed as ambiguous genitalia (n=30). The revised three interview questionnaires, Socio-demographic data sheet, Taylor's Manifest Anxiety Scale and the Parental Coping Strategy Inventory were administered to compare parent anxiety and coping before and after counseling sessions. The total coping score didn't differ significantly at pre and post intervention session (p>0.05), a highly statistically significant difference was observed between the pre and post test mean score of anxiety (p<0.001) and the coping strategies domain were not correlated significantly with total anxiety of parents at pre, post Inventory session (p>0.05). It is concluded that administration of counseling sessions for parents of children with ambiguous genitalia is an effective method to alleviate their anxiety. It is recommended that, the counseling should ideally be by those trained in sexual/gender/intersexes matters, as early as possible put the family in touch with a counselors and support group, and counseling should be multi-staged (at birth, and at least again at age two, at school entry, prior to and during pubertal changes, and yearly during adolescence) as well as examining parental coping strategies at different stages of development would be an interesting avenue for future research.

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1. Introduction:

The first question that usually arises after the birth of any newborn is about the gender of the child. This is easily answered in most cases by simple examination of the external genitalia of the baby. Genitalia are ambiguous whenever there is difficulty in attributing gender to a child based on the appearance of the external genitalia (1, 2). The appearance of the external genitalia is a result of complex interaction between genetic and endocrine processes during fetal development (3).

Ambiguous genitalia are a birth defect or birth variation of the sex organs that makes it unclear whether an affected newborn is a girl or boy. In Egypt , disorders of sex development constitute a significant entity among the birth defect list, where their incidence reaches 1 in 3000 live births (4,5). In the realm of sexual taboos in Egypt , the issue of intersexes or those born with ambiguous genitalia is certainly somewhere near the top of the list. The family denies and often keeps secret that their children have this problem that lead to difficulty to detect the prevalence of the problems (6). The causes

of ambiguous genitalia are 57 percent genetic, 16 percent predispository and 27 percent unknown factors (7).

The diagnosis of ambiguous genitalia in a newborn infant is an emergency that can be difficult to manage; due to importance of gender assignment particularly in less developed areas of the Arab world with a legacy of tribalism, the situation is more complex socially and psychologically Ambiguous genitalia are a major cause of parental anxiety and can create social problems if not probably managed (10). The surgical management of children born with ambiguous genitalia has always been difficult, subject to evolving attitudes and techniques and at times controversial (11). Standard protocols have stressed the need for early diagnosis, gender assignment and appropriate surgery in infancy (12). It is a social emergency in the neonatal period and sex should be assigned as early as possible (13). Once sex is assigned, surgical treatment should commence in early infancy and completed by school age. The diagnostic approach does not differ significantly in

different centers, but the surgical techniques and the timing of surgery differ $^{(14)}$.

Analyzing the attitude of parents of intersexes children, the preference of rearing as male to female is possibly because of the less social stigma attached to an important male than to sterile female, also male are socially independent, where as female are not (15). Consequently, issues of trauma inherent for the families of children born with intersexes conditions often go untreated due to silence surrounding intersexuality (16).

The American Academy of pediatrics (17) now recommends that parents avoid naming the child or registering the birth until the sex is determined and that is should be accomplished quickly, within 2-3 days, the assignment of sex is usually followed by recommendations for genital surgery and parents are told that these surgeries are medically necessary .Generally there has been very little support, education, counseling, or therapy offered to the parents, and parents are poorly educated regarding what it might mean to parent of child with an condition. medically intersexes psychologically^(18,19). Some professionals have suggested that for a parent to refuse genital surgery is akin to child abuse and have recommended using the legal system to force parents to surgically alter their children (20,21). A family coping with the birth of an ambiguous sex organ of their children is a complex issues that require explaining the nature of the child's condition to family, physical and emotional care of the child as well as emotional and psychosocial support to family (22,23).

Parents must be supported in expressing a full range of emotions regarding their child condition particularly in a culture that is silent on this topic and where sex, sexuality and genitalia are not common topics of discussion (24). The family is entitled to have time to understand what they are facing, information to make educated decisions, and resources to develop a support network that can nurture them through the range of emotions they will experience (25,26).

As traditional, social, cultural and religious factors related to the Egyptian community have strong influences on the decision of sex rearing, counseling intervention sessions for parents of children with ambiguous genitalia will be helpful in alleviate anxiety feeling and enhance the coping strategies.

Objectives:

Investigate the effect of counseling sessions on coping strategies and anxiety among Parents of children with Ambiguous Genitalia

2. Subjects and Methods Research Hypotheses:

- 1- Parents of children with ambiguous genitalia be anxious and use unusual coping methods
- 2- Counseling session for Parents of children with ambiguous genitalia will induce positive changes regarding anxiety and coping strategies

Research Design:

A one-group before - after Quasi-experimental design was used

Setting:

The study was conducted at Pediatric Surgery Department of Mansoura University Pediatrics' Hospital and Private Center for Pediatric Surgery at Mansoura city.

Sample

The sample of this study is a convenient sample that included all Parents (30 Parents). All of them were

- Both mother / or father
- Their children not complain form any other disease rather than ambiguous genitalia
- All educational level or occupation
- Both rural and urban dweller
- Their children were diagnosed as ambiguous genitalia
- With or without the history of the same cases

Tools for data collection:

Data was collected by using:

- 1- **Socio-demographic data sheet** that involved child age, birth order, number of hospital admission, residence, parent's occupation and education and presence of same case in the family.
- 2-Taylor's Manifest Anxiety Scale. This scale was used to assess the anxiety symptoms in patients not necessary with generalized anxiety disorder. The Arabic version of this scale was utilized in this study. It consisted of 50 items. It addresses various aspects of anxiety including psychological, somatic or autonomic symptoms. The scale score was 0 for no and 1 for yes, score from 0-16 is considered to be normal, from 17-25 indicates mild anxiety, from 26-36 indicates moderate anxiety, while scores above 36 is indicates severe anxiety (27).
- 3-The Parental Coping Strategy Inventory (PCSI). This scale was used to evaluate the used coping strategies for parents. The scale included (68 items) grouped into 12 subscales , namely : learning (9 items) , struggling (4 items) , interaction with patient (6 items) , interaction with spouse (6 items) , interaction with healthy sibling (5 items) , Emotional support (4 items) , (information support (5 items) , Actual support (4 items) , maintaining stability(8

items) , maintaining an optimistic state of mind (6 items) , searching for spiritual meaning (4 items) , increasing religious activities (4 items) $^{(28)}$.

Procedure:

- -A consent to conduct the study was taking from the hospital director, the researcher contacted to the parent to explain the purpose and procedure of the study and determine the available time to demonstrate the educational session.
- Parents were interviewed individually to collect preassessment data related to socio-demographic, anxiety and coping scales for 2 weeks twice /week.
- Ten sessions distributed on 8 weeks twice /week , it were provided for each $\,$ parents individually , each session was from 30 to 45 minutes
- Each session had its own title and objective according to its content.

Session title

The 1st session: Clear the session purpose, gain parent permission to participate, and collect preassessment data related to socio-demographic, anxiety and coping scales

The 2nd session: Definition and cause of ambiguous genitalia

The 3rd session: How can accept your child as it is, and how can use this acceptance to liberate from your feeling of shame and embarrassment

The 4th session: Recognize the ways of communication with your child, and identify the language used in each developmental stage. The 5th session: Continue to the ways of communication with your child, and identifies the language used in each developmental stage.

The 6th session: Continue to the ways of communication with your child, and identifies the language used in each developmental stage

The 7th session: Importance of social support and what the ways of communication about child problem with other

The 8th session: Importance of religious compliance in the individual life, and use it as coping strategies with feeling of anxiety

The 9th session: Recognize the stages of problem solving

The 10th session: Summarize the content of all previous session, and collect post-assessment data related to anxiety and coping scales

- Parent was interviewed individually to collect postassessment data related to anxiety and coping scales for 2 weeks twice /week.
- Data collection lasted for 12 weeks which started from January to March 2010.

3. Results

Table (1): It is clear from table (1) that, the majority of the children 24(80%) were in the age group more than 6 months, with mean age 43.83. Half of the children were the first birth order 15 (50%). Regarding number of hospital admission, majority of children was admitted to the hospital for less than 5 times 28(93.34%). As regard Positive family history, ambiguous sex was found in about quarter of study sample 8 (26.66%). Regarding parent majority of them was secondary education, more than half of parents 20 (66.66%) have no relative relation, and don't know their child problem and the majority (80%) don't know the causes of this problem.

Table (2): Shows that, among coping domains, mean scores of "Searching for spiritual meaning" and" Increasing religious activities" didn't differ significantly at pre and post intervention sessions (p>0.05). However, the rest of coping domain were highly significant differ at pre and post intervention session (p<0.001).

Generally total coping didn't significant differ at pre and post intervention session (p>0.05).

Table (3): Shows that total anxiety score were highly differ significantly at pre and post intervention sessions (p<0.001).

Table (4): shows that, the mean score of total parent coping at pre and post intervention sessions were differ significantly when present or not present of children with ambiguous genitalia within the family (p<0.05). However, mean score of total parent anxiety didn't differ significantly at pre and post intervention sessions when present or not present of children with ambiguous genitalia within the family (p>0.05).

Table (5): This table shows that, coping strategies domain were not correlated significantly with total anxiety score of parent at pre, post educational session (p>0.05).

Table (1): Sociodemographic characteristics of children and their parent

Items	No	%
Children:		
Age (months)		
<6	6	20
6+	24	80
Mean±SD	43.83	3±30.78
Birth order		
First	15	50
Middle	6	30
Last	9	20
Number of hospital admission		
< 5	28	93.34
5+	2	6.66
Positive family history	22	73.33
No		
Yes	8	26.66
<u>Parent:</u>		
Residence		
Urban	20	66.66
Rural	10	33.33
Mother occupation	15	50
Employee		
House wife	15	50
Father occupation	14	46.66
Employee		
Worker	16	53.33
Parent consongrity	20	66.66
No		
Yes	10	33.33
Mother educational level	_	
< secondary	9	29.99
Secondary +	21	70
Father educational level	5	16.66
< secondary		
Secondary +	25	83.33
Knowing of child problem		
Don't know	20	66.66
Incomplete true answer	9	30
Complete true answer	1	3.33
Knowing the cause of child problem		
Don't know	24	80
Incomplete true answer	6	20

Table (2): Mean score of parent coping strategies at pre and post intervention sessions

	Pre intervention	Post intervention sessions (No=30)		
Coping domain	sessions (No=30)	(Mean ±SD)	Paired	p-value
	(Mean ±SD)		t- test	
Learning	11.30±3.48	25.26±1.92	-23.74	<0.001**
Struggling	7.46±1.79	3.86±2.20	10.06	<0.001**
Interaction with child	8.46±1.87	12.96±2.99	-10.07	<0.001**
Interaction with spouse	8.86±1.79	12.26±2.43	-7.07	<0.001**
Interaction with healthy sibling	3.90±3.37	7.40±5.45	-6.15	<0.001**
Emotional support	5.60±1.92	8.76±2.56	-9.33	<0.001**
Information support	6.03±1.54	10.26±1.70	-12.52	<0.001**
Actual support	3.50±1.10	5.00±1.59	-7.42	<0.001**
Maintaining stability	9.60±2.37	8.33±1.95	2.23	0.03*
Maintaining an optimistic state of mind	9.73±1.61	15.30±1.96	-31.38	<0.001**
Searching for spiritual meaning	5.30±0.95	5.63±0.61	-1.83	0.07
Increasing religious activities	6.06±1.31	6.23±0.62	-0.62	.053
Total	85.83+9.47	121.3+14.76	-17.73	.000

Table (3): Mean score of parent anxiety at pre and post intervention sessions

	Pre intervention sessions (No=30) (Mean ±SD)	Post intervention sessions (No=30) (Mean ±SD)	Paired t- test	p-value (2- tailed)
Total Anxiety score	30.90±6.69	10.93±2.83	15.55	0.001**

Table (4) The relation between parent coping, anxiety and Positive family history

	Positive fa	mily history	t- test	p-value
Total Anxiety /Coping	NO	Yes		
	(Mean ±SD)	(Mean ±SD)		
Total anxiety score	31.46±7.63	29.38±2.73	.747	.461
Coping domain				
Total Learning	10.45±3.48	13.62±2.32	- 2.373	.025*
Total Struggling	7.90±1.34	6.25±2.37	1.870	.096
Total Interaction with child	7.90±1.77	10.00±1.19	- 3.078	.005*
Total Interaction with spouse	9.13±1.93	8.12±1.12	1.764	.092
Total Interaction with healthy sibling	2.86±2.91	6.75±3.01	- 3.201	.003*
Total Emotional support	5.31±1.96	6.37±1.68	-1.452	.168
Total Information support	5.81±1.70	6.62±.74	-1.281	.211
Actual support	3.31±1.21	4.00±.53	-2.131	.042*
Total Maintaining stability	9.50±2.22	9.87±2.90	377	.709
Total Maintaining an optimistic state of mind	9.54±1.71	10.25±1.28	-1.211	.243
Total Searching for spiritual meaning	5.36±1.00	5.12±.83	.600	.553
Total Increasing religious activities	6.27±1.42	5.50±.75	1.913	.068
Total coping score	83.40±9.55	92.50±5.42	-2.530	.017*

Table (5): Correlation between parent coping strategies and anxiety at pre and post intervention sessions

Coping domain	Pre intervention sessions (No=30)		Post intervention sessions (No=30)	
	Pearson Correlation	p-value	Pearson Correlation	p-value
Learning	155	412.	.136	. 475
Struggling	.314	. 091	. 251	.180
Interaction with child	.015	. 938	. 064	.735
Interaction with spouse	165	.384	. 332	.073
Interaction with healthy sibling	. 087	.649	065	. 733
Emotional support	. 096	. 614	. 494**	.006
Information support	.161	. 396	. 404*	.027
Actual support	. 193	. 306	.563**	. 001
Maintaining stability	. 152	.424	.483**	. 007
Maintaining an optimistic state of mind	.424*	.019	. 232	. 217
Searching for spiritual meaning	260	.165	350	. 058
Increasing religious activities	039	. 840	.261	.163
Total	. 152	423.	.384*	. 036

4. Discussion:

Ambiguity of the genitalia in the newborn and children still remains a poorly understood subject that make parent's of the affected children considering this a social stigmata. Therefore parental psychological support should be continuous and must extend to the entire family members, emphasizing the acceptance of the child and using of usual coping with his\her condition (29,30).

The current study indicated that the mean score of parent's anxiety were highly differ significantly at pre and post counseling session, this may be due to , majority of parents didn't know the nature and cause of the child problem (feeling of uncertainty). The concerns that worried the mothers in this study were related to the possibility of sex change, inadequacy of physical appearance and compromise of physiological functions. The difficulties that they emphasized in relation to

treatment were the high cost of drugs such as hormones and travel to distant hospitals to seek treatment.

This corresponding with the study result which revealed that all mothers described emotional reactions of despair , uncertainty, feeling of disgust, non acceptance, insecurity and disappointment were associated with the initial shock caused by that they had child with ambiguous genitalia ⁽³¹⁾.

The goal of coping strategies is to strengthen or maintain individual resources, reduce the source of stress or negative emotions and achieve a balance in individual functioning (32). In this study, among coping domains, mean score of "searching for spiritual meaning" didn't differ at pre and post counseling session, this may be due to all the parents sample were had Islamic religious, that know for most of the people inspit of scientific medical management, they still searching for spiritual meaning and increasing religious activities than usual. This results agrees with the previous study result that, one of the most predictors of emotional adjustment is religion, spirituality is difficult to define because it means different things to different people, spirituality can be defined in various ways: faith in humanity, ethical behavior, concern for others, or interaction in relation to a greater being ^{33,34).} Also another study found that faith and religious coping methods are the most frequently coping strategies among parents who have children with disabilities. Parents appear to involve themselves with religion to greater extent in more stressful situations than in less stressful moments of their life, certain spiritual strategies (35).

Regarding the rest of coping domain as shown in table (2), the mean score were differ after counseling session compared to before. Concerning learning and struggling coping domains, it was improved at post educational session, this may be due to the parent at pre educational session don't know the natural and cause of their children disease or even how to deal with him. The study result revealed that generally parent understand ambiguous genitalia as a chronic illness, the interactions between the child, the family and their social network are affected, The families of intersexes child face the loss of the normal life that they had prior to the diagnosis including the loss of the future life project (36,37). A family evaluation regarding the illness should include the significance of the illness for the whole family and understanding the methods of transferring catastrophic myth, taboos and expectations and the family's belief system throughout generations (38,39).

In relation to interaction with child and spouse coping domain, were considered positive and improved by majority of the parent at post session.

Researchers found that mothers who reported that their husbands shared in housework and child-care roles indicated greater marital satisfaction and flexibility in family functioning (40,41,42) . on the other hand some parent were complaints from fighting with siblings, and the lake of participation of the parents in upbringing or in matters related to the child's treatment such as appointments and meeting with doctors, these higher care giving demands are associated with poorer psychological and physical health state . Mother's also said that they told nothing to their children regarding the pathology and treatment, as they believed the child would not understand the problem, because they did not know how to approach the topic and feared from child's reaction.

Regarding information, emotional, actual support and maintaining stability domain, Parents are frequently bombarded by questions and concerns regarding their child's condition, as well as dealing with societies negative attitude towards individuals who are different . parents who have children with a disability experience greater levels of stress than parents of children without a disability. The extent to which families will experience stress depends on many factors including the child's characteristics, structure of the family, family resources and coping strategies (43,44). Another studies demonstrated that the parent responsible for the child's treatment generally felt overwhelmed, owing to the redistribution of roles or their strategy of coping with the matter. not knowing how to deal with the difficulties presented by the child's condition, the caregiver may choose to leave decisions and the continuity of therapy under the responsibility of the doctors or the other parent^(45,46).

In relation to the coping domain of maintaining an optimistic state of mind , parents before intervention were have a decreased optimistic view concerning their child condition compared to a high level after educational session, this may be due to parent after intervention be understood the nature and prognosis of their children diseases. This come in contrary with study results which mentioned that the mother's expectations for their child's future were optimistic with respect to research and the medical profession, and the results of the surgery^(47,48).

The families abilities to communicate and express their thoughts and feeling is also an important component in health families, open and honest communication involves listening to one another and being sensitive to nonverbal communication being an effective strategy (49). The current show gender differences in coping, women tend to involve themselves more in the emotional roles of caring for the wellbeing of family members, whereas fathers

assume the provider role. This corresponding with studies on effective coping strategies which emphasized that women tend to use a wider range of coping strategies such as reaching out to people, involvement in religious activities and openly expressing their feelings while Men tend to withdraw, keep their feelings inside, and use more harmful types of strategies^(50,51).

The current study illustrated that the mean score of parent anxiety not differ with or without same case of ambiguous genitalia within the family pre and post intervention, this may be due to the strong emotional bond was present between Egyptian family members when one of them had a health problem, they all become anxious regardless present of the same cases previously or not. This is consisted with study result which was indicated that birth of an intersex child can be an emotionally devastating experience for some parents particularly in a culture that is silent on this topic and where sex, sexuality and genitalia are not common topics of discussion (52). While parental coping strategies differ with or without positive family history, this may be due to the parental previous experience will enhance the parental coping strategies in the next experience. This result agrees with the study result which refers to the individual with previous experience using coping strategies directly aimed to problem solving and seeking information that considered more adaptive strategies than those efforts to deny or minimize the situation

5. Conclusion:

Based on the findings of the present study, it can be concluded that: Parents of children with ambiguous genitalia experience a high level of anxiety even when previously present or not present of children with ambiguous genitalia within the family, and counseling sessions will be effective for those parent. A full and honest disclosure is best and counseling must convey strongly to the parents that they are not at fault for the development and the child can have a full, productive and happy life.

6-Recommendation:

- The counseling should ideally be by those trained in sexual/gender/intersexes matters.
- As early as possible put the family in touch with a counselors and support group. It is emphasized that one on one contact with another person having similar experiences can be the most uplifting factor in an alleviating parent's anxiety.
- Counseling should be multi-staged (at birth, and at least again at age two, at school entry, prior to and during pubertal changes, and yearly during adolescence) as well as examining parental coping

strategies at different stages of development would be an interesting avenue for future research.

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