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Parental psycho-affective implications of Ano-rectal malformation in children

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Abstract

Introduction: Ano-rectal malformation (ARM) in children constitutes a serious condition needing an adequate management. Besides, this pathology has a psycho-affective implication on the parents that could be serious in some cases. Reviewing literature, few articles were dealing with this subject. **Materials and methods:** An exhaustive transversal and descriptive study of parents of children suffering from anorectal malformations was undertaken between 01/02/2017 and 15/04/2017. All patients were hospitalized at the pediatric surgery department of Fattouma Bourguiba University Hospital Monastir. Measurements of anxiety and depression levels were performed using Hamilton, Beck and Brief-Cope scales respectively. Measurement of quality of life was carried out using the validated standard Arabic version of the SF-36 methodology. **Results:** A total of 42 parents participated in our study. A score higher than 20 was observed; show the presence of anxiety symptoms, notice in 16.67% of the parents. Depression was observed in 54.8% of parents, among them 28.6% and 7.1% of cases were classified at moderate level and severe level respectively. The assessment of their quality of life (QoL) concludes that 52.4% of parents had scores below 66.7 matching to deterioration. The majority of them were at D2, D4, D6 and D5 levels. The evaluation of coping strategies identified the following common strategies used by parents: religion (83.92%), active coping (76.64%), acceptance (71.42%) and planning (69.64%). **Conclusion:** The psychological and QoL parental repercussion of a child diagnosed with anorectal malformation are indisputable. Social and medical supports are necessary in order to enhance the management and alleviate the implications of this serious condition.

Keywords: Ano-rectal malformation; Anxiety; Coping; Depression; Parental psycho-affective implications; Quality of life

INTRODUCTION

The anorectal malformatiom (ARM) represent a set of congenital anomalies that define the absence of an anal orifice in its normal place. The diagnosis is generally done at birth and it requires the use of surgical treatment within a short period of time. The management of this pathology is quite heavy bearing in mind also some associated malformations that can threaten the vital prognosis from the start. In the long term the functional prognosis is put into consideration in view of the risk of faecal incontinence. We could say that this pathology weighs as much on the parents as the child, since they represent a source of support and are home-care providers. From a parent to another, strategies of adaptation differ and can be inadequate. These new life conditions can be a source of anxiety, intense suffering, and depression causing a deterioration of the parents' quality of life.

Very few studies have treated the subject of the ARM from an angle that evaluates the impact of this pathology on the parents. Within this framework, our work aims to evaluate the psycho-affective effects of the child's ARM on the parents, with the following objectives: to identify the socio-demographic characteristics of the parents of these children, to estimate the prevalence of anxiety and depressive symptomatology, to determine their strategies of adaptation and to measure their quality of life.

METHODOLOGY

This work is based on a comprehensive descriptive cross-sectional study during a period of two and a half months from 01/02/2017 to 15/04/2017, carried out with parents of children treated for ARM in the department of pediatric surgery of the university hospital Fattouma Bourguiba in Monastir. The inclusion criteria were the prior agreement of the parents after being informed about the objectives of the study, while we excluded parents with personal psychiatric history and those whose children died.

Data were collected from parents through direct and/or phone interview since most of the parents lived far away. This collection was done with the help of a pre-established questionnaire containing 47 items that permit the exploration of the general characteristics of the parents (table.1) and the clinic characteristics of the child (fig.1).

Table 1: General characteristics of the parents

Patient characteristics	Effective (n=42)
Sociodemographic characteristics	
middle age	35
Sex ratio	1
Urban origin	64.3%
Marital status of marries	100%
Absence of consanguinity	61.9%
Number of dependent children	2.6
Level of education	73.8%
Presence of professional activity	57.1%
Average socio-economic level	81%
Presence of social security	88.1%
Presence of addictive behaviors	16.7%
Presence of a psychiatric family history	0
Presence of a family history of suicide / TS	0
Presence of a psychiatric personal history	0
Présence d’antécédents personnels médicaux-chirurgicaux	11.9%

Table 2: The anxiety’s gender distribution

	ANXIETY PRESENT	ABSENT
GENDER		
M	0%	60%
F	100%	40%
TOTAL	16.67%	83.33%

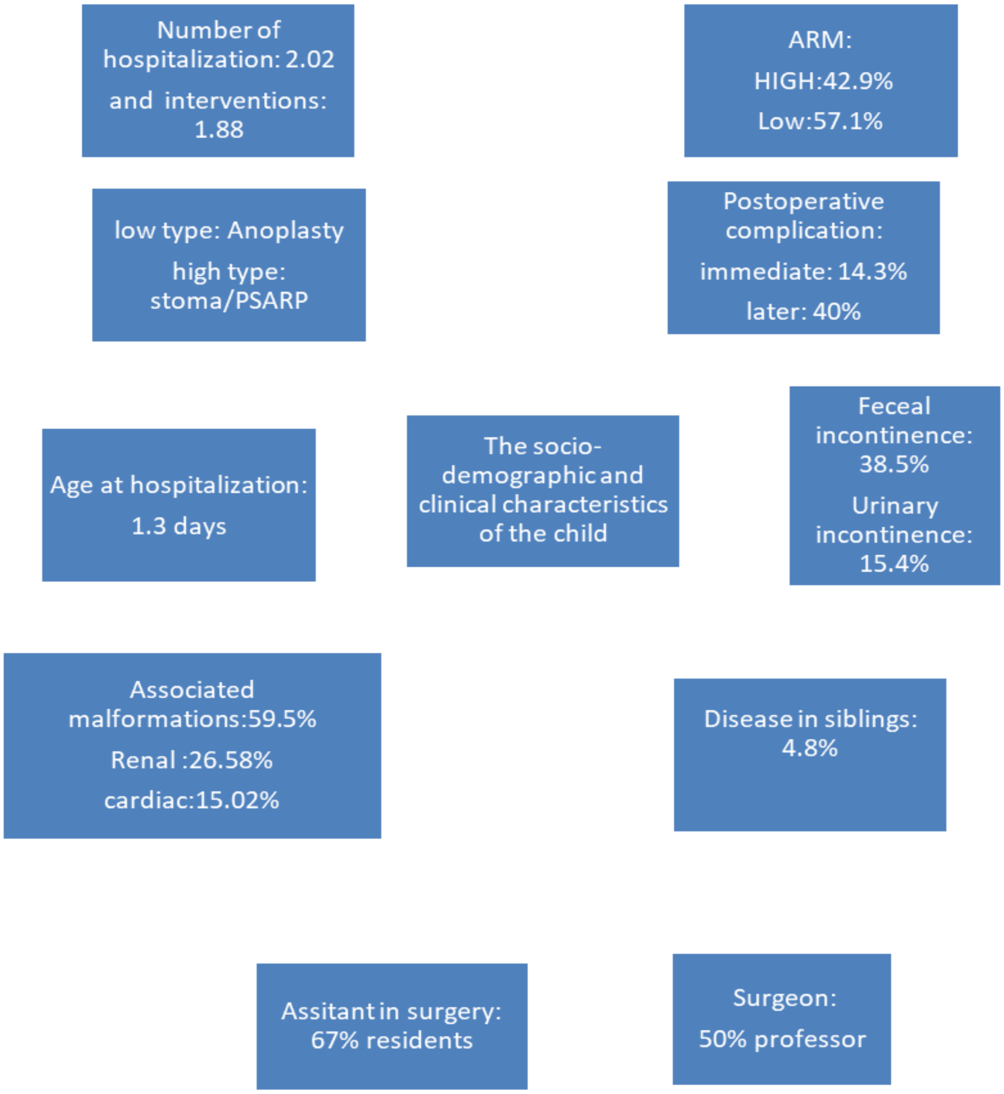

Figure 1: Summary diagram of the socio-demographic and clinical characteristics of the child

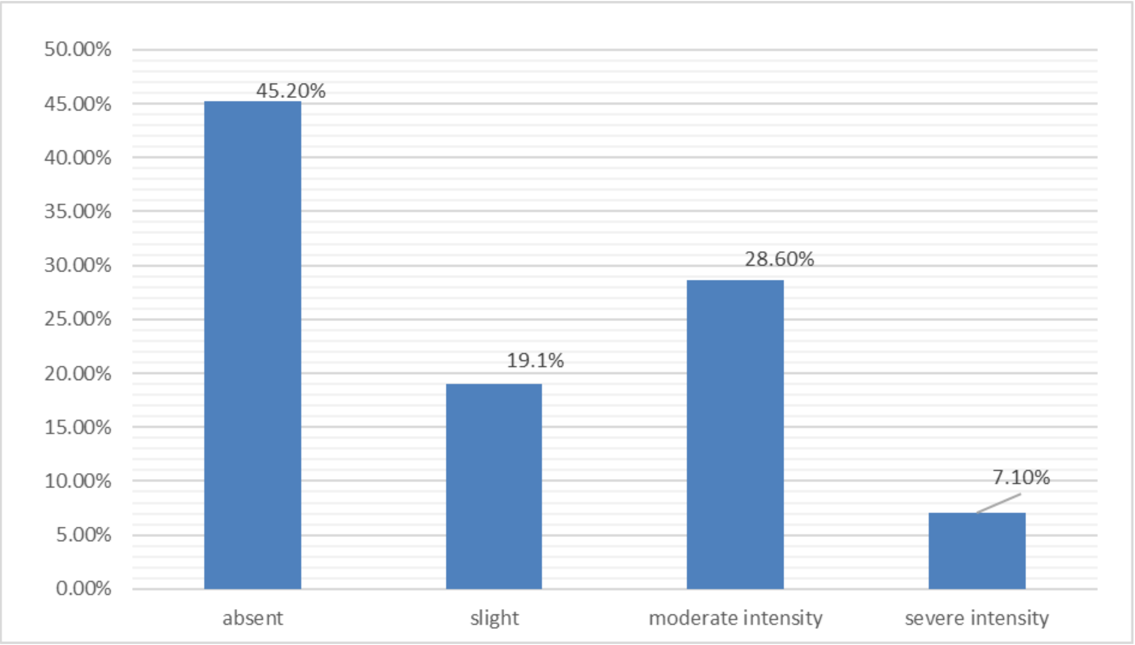

Figure 2: Depression's score obtained by BECK's short form questionnaire

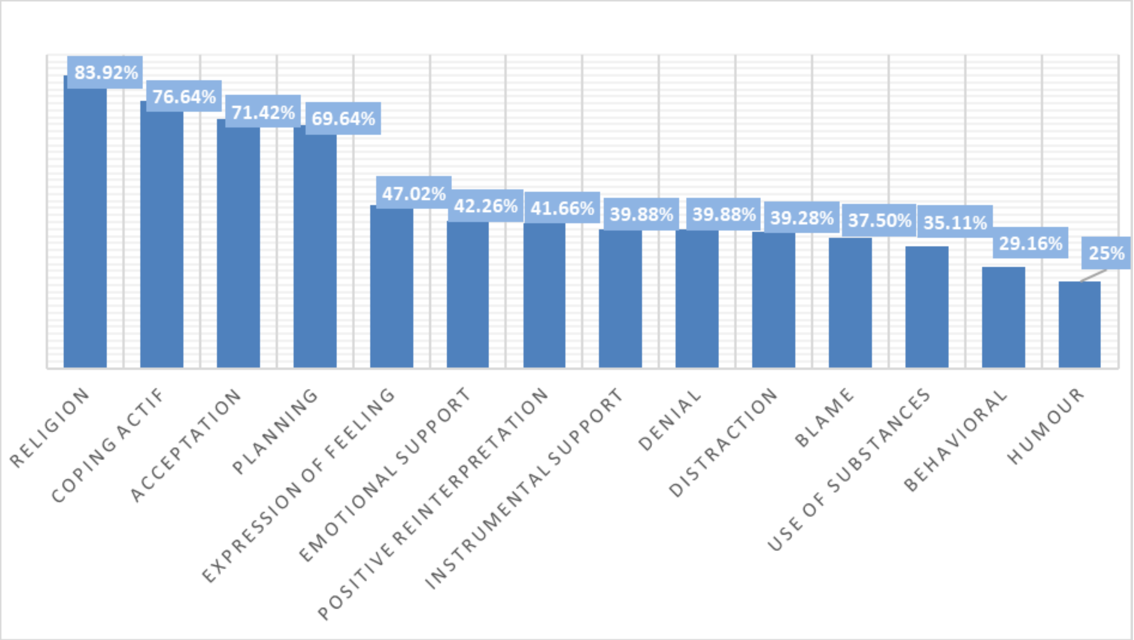

Figure 3: The coping strategies

In order to assess the psycho-affective repercussions of the child's ARM on the parents, to identify the strategies of adaptation and to value their quality of life, we resorted to specific scales.

Evaluation of anxiety symptoms:

To rate the anxiety symptomatology, we used the Hamilton anxiety scale containing 14 items. Each item is rated from 0 to 4. Generally, the accepted threshold for a significant anxiety is 20 out of 56 (annex1).

Evaluation of depressive symptoms:

As for the assessment of depression, it is BECK's short form questionnaire that was used. It contains 13 items (mood, pessimism, sense of failure dissatisfaction, guilt, self –hate, suicide, social with drawal, indecisiveness, body image, work inhibition, fatigue, appetite). Each item is rated from 0 to 3 depending on utterances corresponding to 4 degrees of growing intensity, to finally get 4 thresholds of depression gravity: to recognize an absence of depression (0-4) , a slight depression (4-7), a moderate depression (8-15), a severe depression(≥16).

Evaluation of the quality of life:

For the evaluation of the quality of life, it was done by the SF-36 in its validated Arabic version (1) which contains 36-, grouped in 8 dimensions. An overall average score (SMG) was determined by calculating the average of the rates. An average score for each dimension (SMD) was also calculated to specify which was the most altered. Referring to the threshold of Léan, we admit that an average score <66.7 means an alteration of the quality of life.

Evaluation of coping strategies:

The strategies of adaptation were identified using the board of Brief –COPE (annex2) which contains 14 items, each consisting of two questions. This scale classifies these items in two forms of coping: a problem-centered forms whereas the other is an emotion-centered.

Data analysis

The study data were entered on a computer tool compatible with Excel software, then the statistical analyses were conducted using SPSS 21.0 software for Windows. We calculated simple frequencies and relative frequencies (percentage) for the qualitative variables, averages and standard deviations by determining the extent (extreme values) for the quantitative variables. For the statistical comparisons during the bivariate analysis of the Hamilton and Beck scales with certain socio-demographic and clinical variables, we resorted to Chi-square or Chi-two test. The confidence interval was 95 % with the threshold of $p < 0.05$ considered as significant.

Participants:

The number of participants in our work was 42 parents. The descriptive study concerning the general characteristics of the parents showed that the parents' ages ranged from 24 to 49 years old with an average of 35 years old and a standard deviation of 6.5.

RESULT

Descriptive analysis:

The participants were divided into 21 men (50%) and 21 women (50%), the majority of parents were of urban origins (64.3 %), all of these parents were married, consanguinity was absent in 61.9 % of the cases. The number of dependent children was between

1 and 4 with an average of 2.6, the level of education was high (secondary or higher) at 73.8 % of the people, more than half of the parents (57.1 %) worked with most (33.3%) were workers with an average socio-economic level in 81 % to 88.1 %. In addition, all the parents had no family psychiatric history, 11.9 % of these parents had a personal medical surgical history of which 80% are surgical, and 16.7% presented an addictive behavior.

As far as the characteristics of the child is concerned, the current age was between 1 month and 9 years old with an average of 42.24 months, whereas the age of the first hospitalization ranged from 1 day to 3 days old with an average of 1.3 and a deviation standard of 0.56 this is after excluding the age of 240 days since it is an outlier according to Dixon test. More than half of the cases were low ARMs (57.1 %), while high ARMs presented only 42.9 %. Associated malformations were present in 59.5% of the cases, divided into urogenital malformations (26.58 %), heart defects (15.02 %), limb deformity (7.55 %), trisomy 21 (5.25 %) and hypothyroidism (5.10 %). The surgical operations consisted of anoplasty for the low ARM and a triple intervention (colostomy – PSARP – restoration of continuity) for the high ARM. The operator's doctor was generally a consultant or an assistant (50%), whereas the help was essentially provided by a resident doctor in (66.7 %) of time. Immediate post-operative complications were reported that in 14.3% of cases, most of which (66.6 %) were nosocomial infections requiring appropriate antibiotic therapy. As for late post-operative complications, they were observed in 40% of cases, 64.28% represented by a table of constipation requiring the implementation of a hygienic and dietary adapted diet. Anal dilatations were made in 57.1% of cases: by the doctor in 75% and by the mother in 25%. Fecal continence was preserved in 61.5% of the cases, for the case of incontinence (38.5%), the average frequency was of 9.75 reduced to 3 with a perineal reeducation. Urinary continence was preserved in 84.6% of cases. The total number of hospitalizations ranged from 1 to 8 with an average of 2.02 and a standard deviation of 1.47 and the total number of interventions went from 1 to 10 with an average of 1.88 and a standard deviation of 1.56. In the siblings, there were 4.8 % of heart disease cases.

Analytical analysis:

Regarding the psych affective repercussions on the parents, starting with the assessment of anxiety, 16.67% presented a significant anxiety symptomatology, exclusively feminine (table 2)

As the depression was diagnosed in 54.8% of the cases, in which 28.6% of moderate intensity and 7.1% of severe intensity (figure 2).

To measure the QoL, the overall average scores ranged from 52 to 79 with an average of 65.9 indicating an alteration affecting 52.4% of the parents. The division of the average scores by dimensions showed that the alteration conveyed in descending order the following dimensions: 22.22 % for the physical pains (D2), 47.91% for the perceived health (D4) , 48.8% for life and relationships with others (D6), 64.58% for the vitality (D5), 75.24% for the physical activity (D1), 76.42% for the psychic health (D8), 80.95 % for the limitations due to the physical condition (D2), and 86.5% for the limitations due to the psychic state (D7).

For the study of the coping strategies, the parents adopted the following strategies by descending order : religion (83.92%), active coping (76.64%), acceptance (71.42%), planning (69.64%) , expression of feelings (47.02%) , emotional support (40.26%), positive reinterpretation (41.66%), instrumental support (39.88%), denial (39.88%), distraction (39.28%), blame (37.5%), use of substances (35.11%) behavioral withdrawal (29.16%) and humor (25%).

DISCUSSION

The average age of our patient parents was 35 years old. This average age is superior to the average found between 22-25 years old that was observed in the study of Pruthi and al. [2]

We had a sex ratio (M/F) of 1, whereas in the study of Pruthi and al. [2] a male dominance was observed with a sex ratio (M/F) of 1.6. [3].

The participating parents in our work were all married and mostly of urban origins (64.3 %). These two items were not specified in other studies.

Consanguinity among the parents was found in 39.1% of the cases. For the level of education, it was considerably high since 38.1% had a secondary education level and 35.7% had a higher education level, this is similar to the study results of Pruthi and al. [2] with 38 parents out of 50 participants attended higher education.

The majority of the parents had an occupation (51.1%) with for the most of them an average socio-economic level whereas in the Pruthi and al.'s study [2] the level was low for the majority.

More than two thirds of the parents (88.1%) had social welfare, an item that was not mentioned in other studies. The parents had an average of 2.6 dependent children, an item that was not previously specified in the other studies.

Addictive behaviors were found in 16.7% of cases with the prevalence of more alcoholism at the expense of smoking. An item that we insisted to clarify in our work since it could constitute a coping strategy for the parents.

In our study, it turned out that all our participants had neither a family history of psychiatry, nor personal, nor suicide history or even attempted suicide. While we noted medical illness history in 11.9% of cases, 80% of which had surgical procedure. On the other hand, in the study of Pruthi and al. [15] any history constituted a criterion of exclusion.

The current age of the children ranged from 1 month old to 9 years old with an average age of 42.24 months. In the study of Pruthi and al. [15] the age group ranged from 4 days to 11 years old with an average between 2.5 and 5 years old. As for the study of Equit and al. [3] the average age was of 8.7 years old in an interval of 4.3 to 15.8 years old. During the studies by Nisell and al. [4] and of Ojmyr-Joelsson and al. [5] the current age ranged from 8 to13.9 years old with an average of 10.5 years old.

We observed that in 59.5% of cases there were associated malformations. For the siblings, we noticed two cases of congenital heart diseases (4.8 % of cases). These latter items were not specified in other studies. The total number of hospitalizations ranged between 1 to 8 for a total interventions number ranging between 1 and 10.

As far as the assessment of anxiety is concerned during our work, a significant anxiety symptomatology was present in 16.67% of the parents. According to the study of Ojmyr-Joelsson and al. [5], this anxiety is explained by their child's unclear situation from birth, the impact it can be later, perpetual questions often without clear answers because of the lack of information and explanations long awaited and not obtained by the medical staff. This table of anxiety was exclusively remarked at the female population of our study, in 57.1% of parents of urban origins, whose children had low ARMs, associated malformations, and in 33.33% of cases where we observe a fecal incontinence. These results are closely blended with another work by Ojmyr-Joelsson and al. [6] and the study by Funakosi and al. [7] stating that mothers were more exposed to a higher level of anxiety as they became more involved in the child care; changing the stoma bag, manual anal dilatation maneuvers or regular monitoring of faecal incontinence. As during the work by Pruthi and al. [2] parents had feelings of anxiety, fear, depression, despair about their child's health certainly, but mainly because of the health care system and their financial situation given the low socio-economic level despite the estimation of a low level of psychosocial care in this study. This last point is supported during the work by Hassink and al. [8] that shows that the stress level at the parents whose children have ARM is not different from parents whose children are in perfect health and assigned to primary school, a difference was made when it was a male child who retained faecal incontinence.

For the depression, more than half of the parents who participated in our study presented a depressive picture, of which 28.6% of a moderate degree, mostly mothers (57.9%) as the case for anxiety. While 52.6% of these parents were of rural origins contrary to the anxiety, which could be explained by the lack of means of entertainment for them and for their children, that they are seen to be moved away and left for themselves. Between low and high ARMs, no significant difference was observed. The intensity of depression was greater in the parents whose children had associated malformations and faecal incontinence. This symptomatology aligns with the work by Hassink and al. [8] already mentioned and the work by Ashkani and al. [9] to prove that the risk of depression was higher for the parents whose children had a chronic disease, for parents with low socio-economic level and low educational background.

These observations confirm the importance of talking with parents early on in the preoperative phase, to clarify the intriguing situation of their child as concluded by the work of Aite *et al*. [10]. Indeed, it is at this precarious moment that parents have the greatest need for psychological support according to the study by Aminoff *et al*. [11], to be reassured, not only vis-à-vis the anomaly or the operation but especially the future and the prognosis.

An assessment of the strategies of adaptation was made in our work; it was found that essentially parents adjusted in 83.92% of cases religion, 76.64% active coping, 71.42% acceptance, 69.64% planning. In the study by Awwad-Bawalsah [12], it turned out that parents mainly adopted the strategies of engagement with children with physical, mental and hearing deficiencies, precisely the problem-oriented engagement. It is based on cognitive restructuring and problem resolution. There is also the emotion-oriented engagement that relies on the social contact and the expression of emotions. These strategies could be improved by giving parents the appropriate support, by specialists in the field, to refine them to their needs.

The evaluation of the quality of life was conducted with the aid of the generic scale SF-36 in its standard Arabic version showing that 52.4% of the parents presented deterioration in their QoL. In descending order, the altered dimensions are as follows: physical pains (D2), the perceived health (D4), life and relationships with others (D6), vitality (D5), physical activity (D1), psychic health (D8), the limitations due to physical state (D2), and the limitations due to psychic state (D7). For the study by Pruthi and al. [2], the assessment was based on the WHOQOL-BREF [13]. The overall perception of the QoL was neither mediocre nor excellent. Among the 4 explored fields, the most affected were: the psychological field, the environmental field, and the physical field. Whereas the social field was a little altered. These parents were mainly preoccupied by their child's current conditions, the financial conditions given the low socio-economic level of the majority. In the work by Equit *et al*. [3], the evaluation of the parents' QoL before and after the treatment of urinary incontinence of their children, objectified that the QoL is unchanged still altered, essentially the psychological field which was more deteriorated. Thus, it is essential to help these parents and to assist them throughout the follow-up of their children as it was established in the work of Hassink *et al*. [8] to promote this QoL and minimize the psychosocial burden.

CONCLUSION

To take charge of a child having anorectal malformations from birth, to follow him/her up all the time, to provide him/her with the best medical care and the best conditions involve the parents as much as the medical staff. According to our work, this leads to significant anxio-depressive repercussions on the parents and an alteration of their quality of life. These repercussions cannot be neglected, which encourages to come to their aid. In fact, it is imperative to act as well with the parents as for the children, to provide them with help to overcome the psychological and emotional distress and to guarantee a better quality of life for these parents and thus a better environment for the child. We could act at the level of:

The information concerning the pathology from the moment of the diagnosis; to take time to announce the diagnosis, to give clear explanations about patient care, the stages of the surgery, to prepare them for possible complications, and to be implicit about the prognosis.

The psychological assessment of the parents to prevent the risks of depression, to reduce anxiety, and to guide them to adopt the adequate strategies of coping; in order to get a better quality of life.

Social support with the dream of creating a specialized support association allowing them a better adaptation to the new situation.

Conflicts of interest

There is no conflict of interest.

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