

The Effect of Nursing Care and Follow-up for Mothers of Infants Undergoing Congenital Heart Surgery: A Quasi-Experimental Study

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Research Article

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Abstract

Improvements in congenital heart surgery (CHS) have resulted in an increasing number of infants surviving, but there remain concerns about home care and difficulties experienced by mothers. This study was designed to evaluate the effect of nursing care and follow-up for the mothers of infants undergoing CHS on anxiety, care burden, and self-efficacy. The study was designed as a quasi-experimental study with a pre-test and post-test control group design. The study included 40 mothers whose infants had undergone CHS. Nursing care was provided to the mothers included in the study group through a total of six home follow-ups until the third month after surgery, guided by the North American Nursing Diagnosis Association and Nursing Diagnosis System and Nursing Interventions Classification. Data were collected through Care Needs Identification Form, Spielberger's State-Trait Anxiety Inventory (STAI), Zarit Burden Interview (ZBI), and Parental Self-efficacy Scale (PSE). The mean STAI and ZBI scores for the mothers in the intervention group decreased, while the mean PSE scores increased as the follow-up progressed and it was determined that by the third month, the difference between the mothers in the intervention group and those in the control group in terms of post-test STAI, ZBI, and PSE had become statistically significant. Providing appropriate nursing care practices to the mothers of the infants with CHD in home setting would contribute immensely to decrease the potential problems experienced by the mothers.

Introduction

Congenital heart disease (CHD) is one of the most common congenital anomalies in the world [1]. According to a 2020 report of the American Heart Association, the incidence of CHD is approximately 2.4–13.7 per 1000 live births [2]. In Turkey, the number of infants with CHD born annually is in the range of 12.000–13.000 [3].

Significant achievements in the surgical treatment of CHD have resulted in reduced mortality and morbidity [2]. These advances have led to a shift in the healthcare system focus towards consideration of post-operative care of infant at home [4]. The transition from hospital to home and specifically mothers' experiences of going home for the first time with a fragile infant may cause a stressful situation. The concerns of mothers regarding the transition to home may include a fear of not having sufficient knowledge and skills to provide care to the infant alone, and who to contact when they need counseling [5]. This stress and insufficient support may have a negative impact on the mothers. It was reported that mothers of children undergone CHS experienced anxiety at discharge and required ongoing home care support [6].

Parenting a fragile infant that undergone CHS at home may cause greatest responsibility for infant care in mothers and they may experience caring difficulties [4]. Fulfilling the responsibilities of infant care often requires a significant amount of work throughout the day and night, resulting in the care burden [7, 8]. It is known that mothers of children with CHD experience more care burden than mothers of healthy children [9, 10]. The care burden in mothers is especially high during the discharge period after CHS because of the infant's home care needs [11].

The mothers of the infants undergone CHS may also feel a lack of competence in adjusting to their parental roles as well as in providing care to their infants [4]. Studies evaluating the parental competence of mothers after surgery have reported that the mothers feel less confident and incompetent in infant care [12, 13]. In order to feel self efficient, the mothers need knowledge and skills about the effective ways of taking care of their infant [12]. With the development of parenting self-efficacy, transferring of all knowledge and skills to the care of infants and enhancing positive ways of parenting can be achieved [14].

Healthcare professionals have a key role in decreasing anxiety and the care burden and increasing parental self-efficacy experienced by mothers of infants undergone CHS. Healthcare professionals need to provide mothers with treatment information and care management on infant's home care, share experiences and feelings [5, 15]. A systematic review by March [4] emphasized that nursing interventions make with home visits are needed to optimally manage the transition from hospital to home after the CHS, as well as the process of adaptation to the care. In Turkey, the mothers have no

access to healthcare services other than the routine outpatient clinic follow-ups which are provided after the CHS. However; it is important to maintain the follow-ups not just through hospital controls, rather at home as well, in order to develop a care plan in accordance with the specific requirements of the infant, and to provide effective support for care management. Supporting the mothers in infant's care through the provision of sufficient care would contribute the mothers in maintaining the psychosocial health. The purpose of the study was to determine the effect of nursing follow-up for the mothers of infants undergoing CHS on their anxiety, care burden, and self-efficacy. The hypotheses of the study were:

H₁: Nursing care and follow-up for mothers of infants undergoing surgery due to CHD affects anxiety.

H₂: Nursing care and follow-up for mothers of infants undergoing surgery due to CHD affects care burden.

H₃: Nursing care and follow-up for mothers of infants undergoing surgery due to CHD affects self-efficacy.

Material And Methods

Sample and setting

This study was designed as a quasi-experimental design with pre-tests and post-tests applied to both intervention and control groups. The study was conducted in three pediatric cardiovascular surgery clinics in Ankara between October 2019 and May 2020. The clinics provided diagnostic and treatment services to infants with CHD and their families. These clinics selected by considering that they have similar care protocols and nursing practices for CHS. However, they don't have a written guide for the care of the infants undergoing surgery and nursing follow-up services after discharge. Therefore, the present study was planned and conducted to highlight these points.

The inclusion criteria for the mothers were: (a) living in the city where the study was conducted, and (b) willingness to participate in the study. The inclusion criteria for the infants were: (a) Birth after at least 37 weeks of gestation, (b) absence of any anomaly other than CHD, (c) absence of congenital heart diseases associated with high mortality, such as hypoplastic left heart syndrome, transposition of large arteries, tetralogy of Fallot, and coarctation of the aorta, (d) undergoing CHS for the first time. The exclusion criteria both for mothers and infants were having with physical or mental problems. Seventeen of infants did not meet the inclusion criteria, one mother was unwilling to participate in the study, three infants did not survive after surgery, one infant had been operated upon again during the first month of the intervention, and in two infants, tracheostomy was performed during the second week of the intervention. Thus, the sample was composed of 40 mothers (Fig. 1).

The intervention and control groups

The present study included two groups: the intervention and the control group. The sample size of 20 mothers in each group was calculated after the recommendation of a statistician, as there was no similar study in the literature. Analysis of the statistical power conducted using the program PASS Version 11.0 revealed a power of 94% based on the mean SAI, 85% based on the mean TAI, 87% based on the mean ZBI, and 88% based on the mean PSE at $\alpha = .05$.

Infants meeting the inclusion criteria were grouped according to age (months) and the diagnosis of CHD. The first mother and infant duo meeting the inclusion criteria were included in the intervention group by the drawing of lots method, while the second mother and infant duo with matching criteria (age (months) and diagnosis of CHD) was assigned to the control group. The assignment process was repeated for the rest of the mother and infant duos. The groups were homogeneous according to the age (months) and diagnosis of congenital heart disease ($\chi^2 = .000, p = 1.000$) (Table 1).

Data Collection Form

Care Needs Identification of the Mothers of Infants with CHD Form

It was prepared after reviewing the literature for the relevant variables [11,16,17]. The section on the characteristics of the mother and infant was included in the first part of the form, which contained questions about the infant's age, gender, gestational week, diagnosis, mother's age, educational level, employment status, income status, and the number of children in the family. The second part of the form included questions prepared according to Gordon's Functional Health Patterns Model, which comprised 11 categories of health to determine the care needs of mothers in nursing follow-up.

After the development of the form, content validity was controlled by sending the form to five Paediatric Nursing Specialists. The identification form was finalized based on the opinions obtained from the experts.

Spielberger's State-Trait Anxiety Inventory

The state anxiety inventory describes how the individual feels at a certain time and under certain conditions. The trait anxiety inventory describes how the individual generally feels. It is a four-point Likert-type scale having 20 items in each section. The scores obtained from both scales vary between 20 and 80. Based on the scale, 20–39 points indicate "mild anxiety", 40–59 points suggest "moderate anxiety", 60–79 points indicate "severe anxiety", and 80 points suggest "panic" [18,19]. High scores indicate high anxiety levels, whereas low scores indicate low anxiety levels. In the present study, Cronbach's Alpha values were determined as .94 for state anxiety inventory and .90 for trait anxiety inventory.

Zarit Burden Inventory

It is a five-point Likert-type scale consisting of 22 items determining the effect of caregiving on an individual's life. This inventory is evaluated based on the total score, and the minimum and maximum scores of the inventory are 0 and 88 points, respectively. Based on this inventory, 0–20 points indicate "little/no burden", 21–40 points suggest "moderate burden", 41–60 points indicate "severe burden", and 61–88 points suggest "severe burden". A high scale score indicates that high distress is experienced. The validity and reliability of this inventory in the Turkish context were determined by İnci and Erdem [20]. Cronbach's alpha for the present sample was .96.

Parental Self-efficacy Scale

It was developed by Kılıçaslan in 2007 to determine the personal judgment of new parents with 3–6-month-old infants about their competencies in a parental role. It consists of 18 items and is a 5-point Likert-type scale. The scores obtained from the scale range between 18 and 90. A higher score obtained from the scale indicates a higher perception of self-efficacy [21]. Cronbach's alpha for the present sample was .93.

Nursing Care Plan for Mothers of Infants with CHD

Based on the results of the preliminary application of the care needs identification form and the relevant literature [13,16,22,23], five nursing diagnoses were established for mothers in the nursing care plan. The nursing diagnoses and nursing interventions were developed according to the guidelines of the North American Nursing Diagnosis Association (NANDA) and the Nursing Diagnosis System and Nursing Interventions Classification (NIC) [24]. The content was validated using Davis' technique, and the validity levels of the items were calculated between .81 and 1.00. The content validity index was observed to be acceptable for all the items [25].

Training Booklet

Based on the results of the preliminary application of the care needs identification form, the topics concerning the care of the infant were established, such as whether the mothers had insufficient information and wanted to learn. According to the relevant literature [11,16,17,26,27] and the findings of the preliminary application, a training booklet was prepared, which included basic information related to CHD as well as information regarding the care of infants after surgery

(nutrition, bath, sleep, surgical area care, activity, pain management, administration of medication, chest physiotherapy, infection control), coping with stress, and maintaining the mother-infant communication.

Following the development of the nursing care plan and training booklet, content validity was controlled by sending it to four Paediatric Nursing Specialists and one clinic nurse. The nursing care plan and training booklet was finalized according to the opinions obtained from the experts.

Intervention

The researcher visited the clinics daily. Following the identification of an eligible participant, the researcher explained the study to the infant's mother. For both intervention and control group, the Care Needs Identification Form, STAI, ZBI, and PSE were administered through a face-to-face interview on the day when the infants were shifted from the intensive care unit to the clinic.

An individual care plan was prepared for each mothers in the intervention group in accordance with the care needs determined through the needs identification form. The nursing diagnosis and nursing interventions specific for the mothers were selected from the nursing care plan. The priority order, nursing interventions and etiology of the five nursing diagnoses are structured specifically for each mother. Nursing interventions were identified according to the NIC based on the obtained nursing diagnoses. After this stage, home follow-ups was performed in line with the following steps at each visit. Six home follow-ups were performed until the third month after surgery. The first home follow-up was performed on the first day after discharge. The second home follow-up was performed three days after the first home follow-up, the third home follow-up was performed one week after the second home follow-up, the fourth home follow-up was performed in the first month after surgery, the fifth home follow-up was performed in the second month after surgery, and the sixth home follow-up was performed in the third month after surgery. Each home follow-ups lasted approximately 60–90 min. The mothers received training for care requirements through the training booklet and nursing care was provided during the home follow-ups. Each home follow-up, problems experienced by the mother in care requirements were re-evaluated. If a priority need was detected during the home follow-up, it was addressed immediately. Nursing care activities (preparation and administration of medication, bathing of the infant, care of the surgical area etc.) were performed with the mothers to improve care skills. Also, the difficulties, experiences and feelings of the mothers regarding care practices were discussed during home follow-ups. For the control group, no other care was provided outside of what was offered at the hospital.

In the intervention group, STAI, ZBI, and PSE were administered once again during the sixth home follow-up. In the control group, STAI, ZBI, and PSE were administered once again in the routine controls of the hospital during the third month after surgery.

Ethical considerations

Ethics-related approval were obtained from a University's Non-Invasive Clinical Trials Ethics Committee (Number:16969557–568). Moreover, written permissions were obtained from the hospitals to conduct the study. Informed consent was obtained from the participating mothers in writing. The present study complied with the ethical rules for human experimentation stated in the Declaration of Helsinki. Data collection and all home monitorings were conducted by the first author. All mothers in the intervention group received six regular home follow-ups from the first author who had experiences in a pediatry care unit.

Statistical Analysis

The data were analyzed using the program IBM Statistical Package for Social Sciences (SPSS) for Windows version 21.0. For the analysis of the descriptive data, numbers and percentages were used as the discrete data, whereas the continuous data were presented as mean \pm standard deviation. The student's t-test was employed to determine the difference between

the independent groups, Pearson's chi-squared test and Fisher's exact test were employed to determine the relationship between two independent categorical variables, and Cochran's Q-test was used to determine the relationship among more than two dependent categorical variables.

Results

Table 1 presents the demographic data for mothers and infants. No significant demographic differences were observed between the groups.

Nursing Diagnosis

During the first home follow-up, it was determined that all of mothers in the intervention group (100.0%) had deficient knowledge, difficulty in the caregiver role, and ineffective management of health/treatment. Furthermore, 85.0% of the mothers were at risk of ineffective coping, while 75.0% were at risk of deterioration in attachment. A significant reduction in time was established for dealing with all the problems as a result of the provision of nursing care and follow-up ($p < .05$) (Table 2).

Mother's anxiety

The mean pre-test SAI scores for the mothers were similar in both intervention (58.70 ± 7.664) and control (59.05 ± 4.084) groups ($t = -.180, p = .858$). The mean post-test SAI scores of the mothers in the intervention group were observed to decrease to 37.90 ± 3.370 after the nursing care and follow-up ($t = 13.513, p < .0001$), whereas that of the mothers in the control group was 57.60 ± 4.031 ($t = 1.828, p = .083$) at the third month after surgery. The mean post-test SAI scores of the intervention group and the control group were statistically different ($t = -20.171, p < .0001$) (Fig. 2).

The mean pre-test TAI scores for the mothers were similar in both intervention (52.60 ± 5.852) and control (53.05 ± 8.178) groups ($t = -.200, p = .843$). The mean post-test SAI score of the mothers was observed to decrease to 34.35 ± 4.556 after the nursing care and follow-up in the intervention group ($t = 27.211, p < .0001$), whereas that of the mothers in the control group was 54.30 ± 5.181 ($t = -.586, p = .565$) at the third month after surgery. The mean post-test TAI scores of the intervention group were statistically different from those of the control group ($t = -14.873, p < .0001$) (Fig. 3).

Mother's care burden

The mean pre-test ZBI scores for the mothers were similar in both intervention (50.80 ± 5.899) and control (50.30 ± 10.716) groups ($t = .183, p = .856$). The mean post-test ZBI score of the mothers in the intervention group decreased to 30.80 ± 4.969 after the nursing care and follow-up ($t = 12.996, p < .0001$), whereas that of the mothers in the control group was 51.05 ± 13.072 ($t = -.640, p = .530$) at the third month after surgery. The mean post-test ZBI scores of the intervention group and control group were statistically significantly different ($t = -6.475, p < .0001$) (Fig. 4).

Mother's parental self-efficacy

The mean pre-test PSE scores for the mothers were similar in both intervention (60.60 ± 7.856) and control (61.20 ± 6.985) groups ($t = -.255, p = .800$). The mean post-test PSE score of the mothers was observed to increase to 75.15 ± 3.910 after the nursing care and follow-up in the intervention group ($t = -6.016, p < .0001$), whereas that of the mothers in the control group was 59.35 ± 5.518 ($t = 1.420, p = .172$) at the third month after surgery. The mean post-test PSE scores of the intervention group and the control group were statistically significantly different ($t = 10.448, p < .0001$) (Fig. 5).

Discussion

The results of this study have revealed that mothers of the infants undergone CHS exhibited decreased level of maternal anxiety and care burden, increased level of parental self-efficacy after the nursing care and follow-up at home addressing the care needs of the mothers. In order to avoid psychosocial problems in mothers and enhance the positive development of the care of infants undergone surgery, mothers should be followed-up closely after surgery [28].

Nursing Diagnoses

In the first home follow-up, the most common problems noted among the mothers in the intervention group were deficient knowledge, difficulty in a caregiver role, and ineffective health/treatment management. The literature includes studies reporting the maternal problems such as the lack of knowledge regarding home care after surgery [29], ineffective coping and difficulties in providing care to the infants, and attributes these problems to the need for support during home care [11,16]. It was identified that insufficient knowledge and skills as the leading factors contributing to postdischarge stress in mothers [8]. Constant evaluation of the level of information, health training, and counseling for infant care during home follow-ups are the nursing interventions that help to eliminate the lack of knowledge. The prevalence of difficulty in the caregiver role and ineffective health/treatment management reduced to 10%, and 5% after the provision of nursing care during home follow-ups to the mothers in the intervention group for consulting, training regarding treatment, medication management, supporting the caregiver and helping the self-care of infants. This result suggested that the nursing care which was provided during home follow-ups to the mothers in accordance with their care needs was effective in reducing the difficulties in the caregiver role, as well as the management of the infant's health/treatment at home.

Mother's anxiety

Previous studies have reported that mothers of children who had CHS experience "moderate" to "severe" anxiety [6,8,30,31]. In a study conducted to determine the factors resulting in anxiety among mothers after CHS, it was stated that insufficient knowledge regarding infant care after surgery was a factor that increased anxiety [32]. Therefore, the factors causing anxiety should be identified [6], and interventions should be planned for adaptation to home care [4]. In this study, mothers' anxiety scores within the study group during the baseline were similar to those in past studies; however, the mean anxiety scores of the mothers in the intervention group decreased from "moderate" level to "mild" level after home follow-ups, when compared to the control group, were highlighting a potential area of effectiveness with the intervention. Determination of the cognitive, emotional, and social needs of mothers, supporting the participation in providing care, and provision of the information regarding the effective coping methods during home follow-ups, are the nursing interventions that decrease the anxiety of mothers. Nursing support received might enable mothers to cope with stress and anxiety more easily. Therefore, it may be inferred that the remain of high level of anxiety in the mothers is inevitable if the mothers of the infants undergone CHS are not sufficiently supported.

Mother's care burden

Care burden of the mothers may increase due to the special care needs of the infant undergone CHS [11,33], the lack of information, and not being ready to provide care to the infant at home [11,34]. Sabzevari and Nematollahi reported that the care burden of the mothers was closely related to the difficulties experienced by them while caregiving, and it was important to provide training and psychosocial support by the nurses for the development of care skills [10]. Perceived care burden can be alleviated by supporting mothers during infant care [34,35], and increasing their coping skills [36] with nursing care. In this study, sharing experiences regarding the care difficulties, performing the infant care needs such as nutrition, bathing, preparation and administration of medication, counseling, improving the participation in care during home follow-ups are the nursing interventions that decrease the care burden of mothers. The nursing care provided to the mothers of the infants with CHS positively affected care burden, this problem was observed to continue when there was no intervention.

Mother's parental self-efficacy

Mothers may experience a feeling of inadequacy in parenting while trying to meet many complex care needs of their infants during the post-operative period. It has been reported that the mothers of infant undergone CHS feel incompetent, particularly in feeding, pain management, insicion care and infection control [11,13,23]. The previous studies have reported that the training regarding the care of infants and children having CHS increased the self-efficacy of the mothers [12,23]. The common theme of these studies is that the educational intervention was used to increase the self-efficacy of mothers in care. However, besides the education, it is believed that nursing follow-up in the home environment are important in developing self-confidence and care skills, which are among the most important components of parental self-efficacy and effective maintenance of infant care after surgery. Fulfilling the caring requirements of mothers would improve parental self-efficacy. In this study, apart from education, performing infant care practices with mothers in the intervention group, as well as nursing interventions such as counseling and improving participation in care, were effective in increasing the self-efficacy of mothers.

Limitations

The present study had certain limitations. First, it is not clear whether the mothers in the control group received information on infant care from their social sources, other than from the standard care provided by the hospitals. Second, the results of this study cannot be generalized since the care needs of mothers may differ from person to person, although the power of this study was good.

Conclusion

Turkey, and a significant majority of developing countries, lack programs for monitoring of the infants undergone CHS and their mothers. The results of this study demonstrated that nursing care and follow-up in the home environment addresses the care needs of the mothers after CHS, resulting in a decrease of anxiety, care burden, and the problems experienced by mothers, along with an increase in self-efficacy. Therefore, the results of this study may be considered important in terms of providing evidence-based information, supporting the inclusion of such services in national healthcare programs.

Declarations

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The authors declare they have no financial interests.

Data Availability

All data and materials, as well as software application, support our published claims and comply with feld standards.

Conflict of Interest

No conflict of interests have been declared by the authors.

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Tables

Table 1 Descriptive characteristics of groups

Characteristics	Intervention (n=20)		Control (n=20)		Statistical analysis	
	n	%	n	%	χ^2	<i>p</i>
Mother's age						
20-30	16	80.0	17	85.0	0.417*	0.748
31-40	4	20.0	3	15.0		
Educational level						
Secondary school	2	10.0	3	15.0	0.630**	0.730
High school	11	55.0	10	50.0		
University	7	35.0	7	35.0		
Employment						
Employed	9	45.0	7	35.0	6.167*	0.187
Unemployed	11	55.0	13	65.0		
Number of children						
One	12	60.0	10	50.0	1.145*	0.605
Two and over	8	40.0	10	50.0		
Income level						
Income is less than expense	7	35.0	6	30.0	1.778**	0.411
Income is equal to expense	11	55.0	12	60.0		
Income is more than expense	2	10.0	2	10.0		
Getting support from spouse for infant care						
Yes	6	30.0	7	35.0	0.417*	0.748
No	14	70.0	13	65.0		
Gender						
Girl	7	35.0	7	35.0	0.000*	1.000
Boy	13	65.0	13	65.0		
Infant's age (months)						
1-3 months	8	40.0	8	40.0	0.000**	1.000
4-6 months	5	25.0	5	25.0		
7-9 months	3	15.0	3	15.0		
10-12 months	4	20.0	4	20.0		
Type of CHD						
ASD	2	10.0	2	10.0	0.000**	1.000
VSD	3	15.0	3	15.0		

ASD+VSD	8	40.0	8	40.0		
VSD+PDA	1	5.0	1	5.0		
Pulmonary Stenosis	2	10.0	2	10.0		
Tricuspid Atresia	3	15.0	3	15.0		
Truncus Arteriosus	1	5.0	1	5.0		
Time of diagnosis					0.533*	0.716
Antenatal	4	20.0	6	30.0		
Birth or shortly after	16	80.0	14	70.0		

* Fisher's Exact Test. ** Pearson Chi-Square.

Table 2 Distribution of nursing diagnoses determined in mothers in the intervention group (n=20)

Nursing Diagnoses	Home follow-ups												Statistical analysis	
	Follow-up 1		Follow-up 2		Follow-up 3		Follow-up 4		Follow-up 5		Follow-up 6		Q	p
	n	%	n	%	n	%	n	%	n	%	n	%		
Deficient knowledge	20	100.0	20	100.0	18	90.0	9	45.0	5	25.0	–	–	71.299*	<0.0001
Difficulty in the caregiver role	20	100.0	20	100.0	17	85.0	12	60.0	7	35.0	2	10.0	58.286*	<0.0001
Risk of deterioration in attachment	15	75.0	15	75.0	14	70.0	7	35.0	3	15.0	–	–	55.424*	<0.0001
Ineffective coping	17	85.0	17	85.0	13	65.0	10	50.0	4	20.0	1	5.0	54.918*	<0.0001
Ineffective health / treatment management	20	100.0	20	100.0	16	80.0	12	60.0	6	30.0	1	5.0	63.723*	<0.0001

* Cochran's Q Test ($p < 0.05$).

Figures

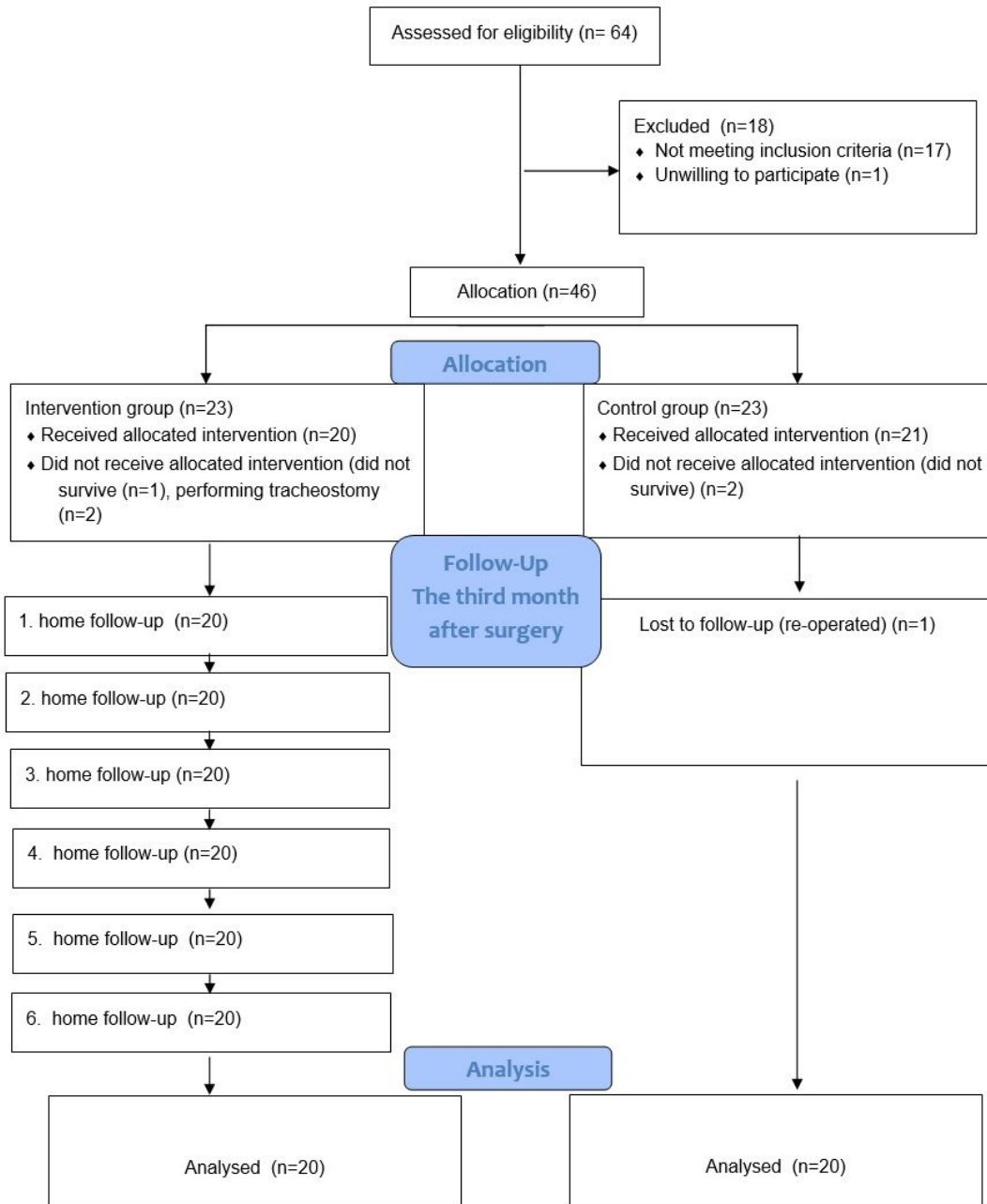


Figure 1

Consort diagram

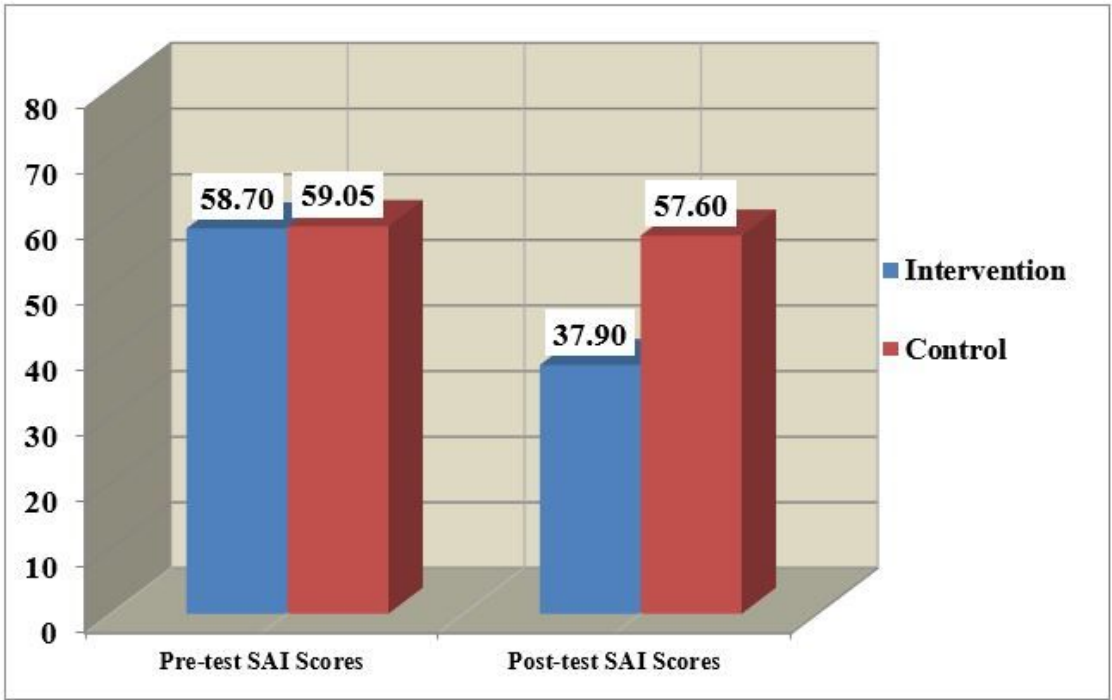


Figure 2

Comprasion of the mean pre-test and post-test SAI scores by groups



Figure 3

Comprasion of the mean pre-test and post-test TAI scores by groups

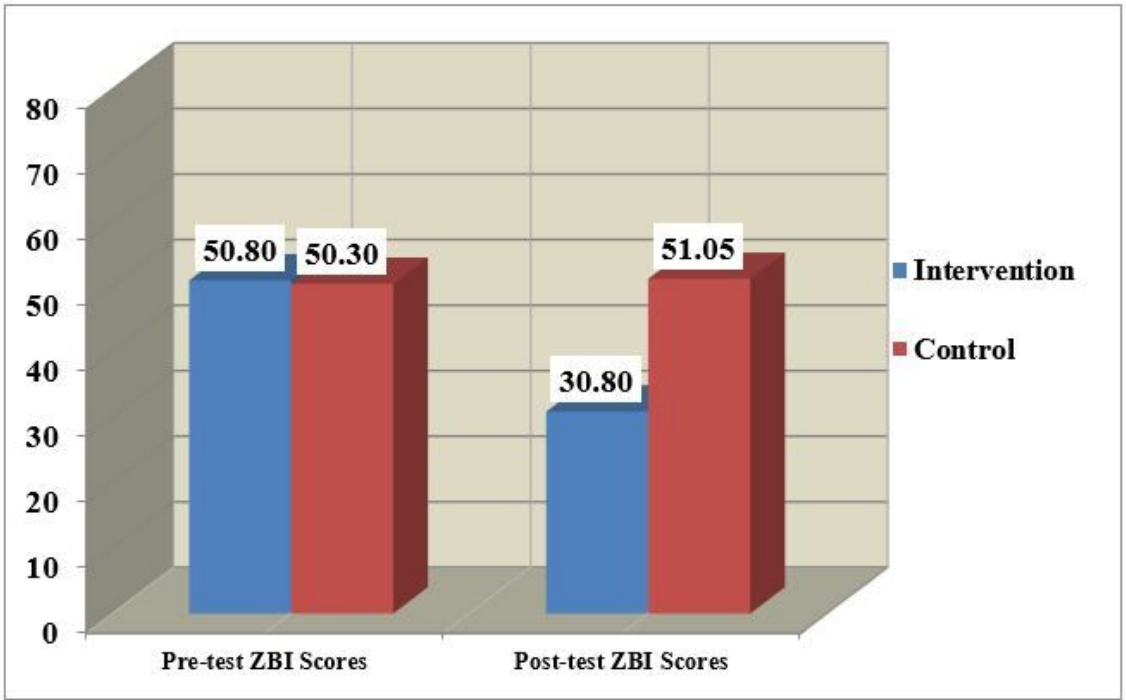


Figure 4

Comprasion of the mean pre-test and post-test ZBI scores by groups

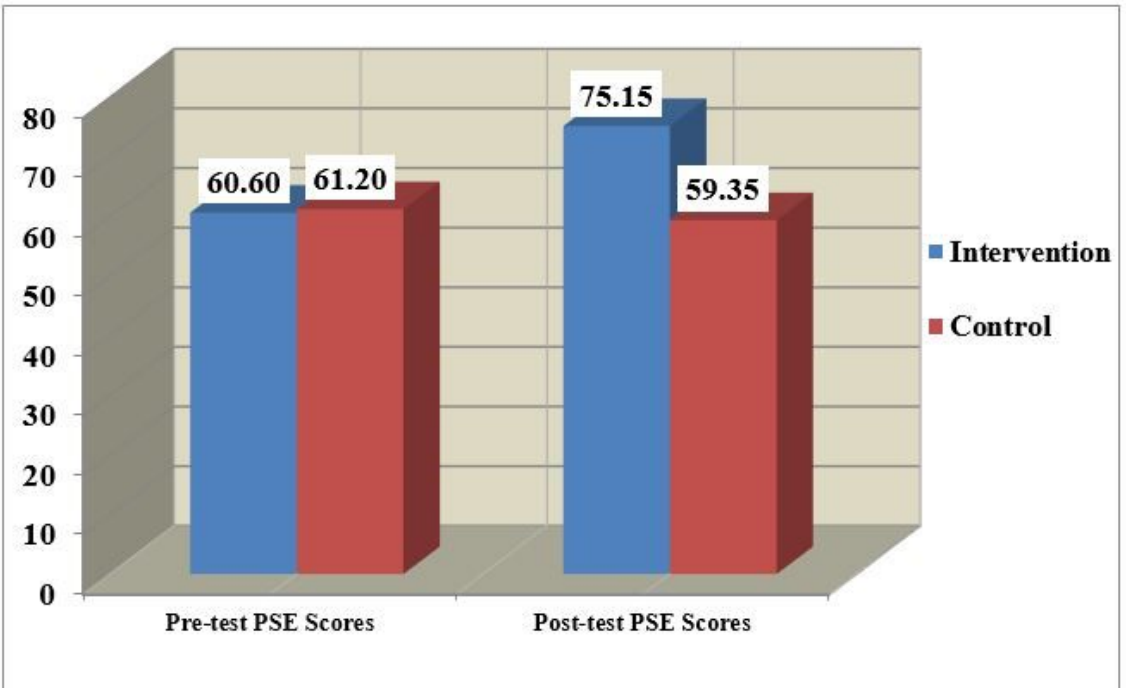


Figure 5

Comprasion of the mean pre-test and post-test PSE scores by groups