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Opinions, Attitudes and Experiences of Caregivers Before and After Their Children's Gastrostomy Procedure: A Systematic Review Of Quantitative Studies

Çocuklarda Gastrostomi Prosedürü Öncesi ve Sonrası Ebeveynlerin Tutumları, Deneyimleri ve Bakış Açıları: Kantitatif Çalışmaların Sistematik Derlemesi

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ABSTRACT

It is important to understand caregivers' need for support from healthcare provider and the effect of gastrostomy tube feeding (G-tube feeding) on the lives of children and their caregivers before and after gastrostomy procedure. This systematic review aims to identify the opinions, attitudes and experiences of the caregivers related with G-tube feeding.

We reviewed quantitative studies in English that deal with opinions, experiences and attitudes of caregivers before and after children's gastrostomy procedure. In consultation with a medical librarian, we reviewed quantitative studies on our subject that were published up to 10 May 2015 by using five electronic databases, namely, CINAHL, PubMED, PSYCINFO, SCOPUS and Ovid Cochrane database of Systematic Reviewsfor quantitative studies. The quality of reviewed studies was evaluated by using JBI Critical Appraisal Checklist for Observational Studies.

We identified 1897 citations and only eight studies from the citation list met the inclusion criteria. Five studies collected data after G-tube placement whereas the remaining three studies collected data during both the pre-procedural and post-procedural period. In six of these studies, outcomes were assessed by using objective criteria. None of the studies used questionnaires, whose reliability and validity were assessed for the country that the studies were conducted at. Caregivers in five of these studies expressed positive outcomes, such as, decreasing stress levels, increased satisfaction for the children and their parents, and improvements in the quality of life and the communication between the children and their parents. Three studies found both positive and negative impacts of G-tube placement on the lives of children and caregivers. Factors, such as, difficulty in reaching a final decision on G-Tube placement, inadequate information provided by healthcare professionals, restricted mobility, stress related with G-tube feeding, insufficient postoperative education program, and fear of unintentional loss of the gastrostomy button, were expressed as negative outcomes of G-tube feeding.

Although some studies state that feeding with gastrostomy tube facilitates the lives of children and caregivers, some studies show that the gastrostomy tube adversely affects the lives of children and families. As a result, healthcare professionals should tend to inform families about all aspects of the procedure during the gastrostomy procedure, knowing these positive and negative consequences from studies.

Key Words: Caregivers, Gastrostomy procedure, Systematic review

ÖZ

Gastrostomi prosedürü öncesi ve sonrası tuple beslenmenin çocuk ve aile üzerindeki etkisini ve sağlık profesyonellerinden destek gereksinimini anlamak önemlidir. Bu sistematik derlemenin amacı, bakım verenlerin ve/veya ebeveynlerin gastrostomi tüpü ile beslenme deneyimlerini, görüşlerini ve bakış açılarını tanımlamaktır. Sağlık hizmeti sağlayıcılarından destek alma ihtiyacını ve gastrostomi prosedürü öncesi ve sonrası tüple beslenmenin çocuk ve ailesinin yaşamı üzerine etkisini anlamayı artırmak için bakım verenlerin ve/veya ebeveynlerin gastrostomi tüpü ile beslenme deneyimlerini, görüşlerini ve bakış açılarını tanımlamaktır. Bu sistematik derleme çocuklarda gastrostomi prosedürü öncesi ve/veya sonrası ailelerin ve/veya bakım verenlerin tutumu, deneyimlerini ve bakış açısını tanımlayan sadece İngilizce dilindeki kantitatif çalışmaları içermektedir. Medikal kütüphaneci danışmanlığında, CINAHL, PubMED, PSYCINFO, SCOPUS

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ve Ovid Cochrane veri tabanı dahil olmak üzere beş adet elektronik veri tabanını 10 Mayıs 2015 tarihine kadar kapsamlı bir şekilde tarandı. Kantitatif çalışmaların niteliği Gözlemsel Çalışmalar için JBI Kritik Değerlendirme Kontrol Listesi kullanılarak değerlendirildi. Literatür taramasında 1897 kaynak belirlendi. Tarama listesinden sekiz çalışma dahil edilme kriterlerini karşıladı. Verilerin elde edilme zamanı, beş çalışmada gastrostomi tüpü yerleştirme öncesi üç çalışmada gastrostomi tüpü yerleştirme öncesi ve sonrasıydı. Tüm çalışmalarda kullanılan anketlerin ülkeler için geçerliliği yapılmamıştı. Beş çalışmada, katılımcılar gastrostomi tüpü ile birlikte stresinin azaldığını, hem çocuk hem de anne-baba için memnuniyetin arttığını ve ebeveyn-çocuk iletişiminin geliştiğini, yaşam kalitelerindeki iyileşmeyi hissettiğini bildirdi. Üç çalışmada, sonuçlar hem çocuklar hem de aileleri ve bakım verenlerin yaşamları üzerinde olumlu ve olumsuzdu. Tüple beslenme ile ilişkili olumsuz faktörler gastrostomi tüpü yerleştirilmesine karar vermede zor anlar yaşama, yetersiz bilgi, aktivitenin kısıtlanması ve tüp beslenmesi ile ilgili stres, taburculuk eğitiminin yetersiz hazırlanması, gastrostomi butonunu kaybetme korkusuydu. Bazı çalışmaların gastrostomi tüpü ile beslenmenin çocukların ve bakım verenlerin yaşamlarını kolaylaştırdığını açıklamasına rağmen, bazı çalışmalar gastrostomi tüpünün çocukların ve ailelerin yaşamlarını olumsuz etkilediğini göstermektedir. Sonuç olarak sağlık profesyonelleri çalışmalardan elde edilen bu olumlu ve olumsuz sonuçları bilerek gastrostomi prosedürü sırasında ailelere işlemin tüm yönleri hakkında bilgi verme eğiliminde olmalıdır.

Anahtar Sözcükler: Görüş, Gastrostomi prosedürü,Sistematik derleme

INTRODUCTION

Enteral nutrition therapy is the preferred nutritional support for pediatric patients diagnosed with cerebral palsy, cancer, organ transplantation, graft versus host disease, anorectal malfunction, pancreatitis, cystic fibrosis (1-3). Enteral nutrition via percutaneous endoscopic gastrostomy (PEG) has become "one of the most preferred alternatives to nutrition support for pediatric patients with preserved intestinal function but inadequate or no independent oral food intake". Delivery of nutrition directly into stomach by using gastrostomy tube (G-tube) is an easy, safe and physiologically better way of nutrition intake since this method enables pediatric patients to benefit from anti-infectious effects of the stomach acid and peristaltic movements and mixing function of stomach (4).

G-tube feeding has various effects on daily lives of pediatric patients and their caregivers. Exiting studies described diverse outcomes before and after gastrostomy procedure with positive and negative impacts on children and caregivers (5). Some of the caregivers may be reluctant to proceed with PEG even after they were informed about the advantages and disadvantages of the procedure (6,7). Prior to gastrostomy procedure, parents of pediatric patients may not be not sufficiently informed so that they may find it difficult to reach to a final decision regarding gastrostomy procedure (8). After the gastrostomy procedure, some of the caregivers expressed positive physical impacts of the procedure on their children, including, increase in weight, improved respiratory status and better quality of life(9). On the other hand, negative impacts of gastrostomy procedure, such as minor tube complication, difficulties with tube, undesired weight gain, loss of pleasure from eating and parental sleep, were also recorded (8-11,16). For example, in one of the studies that analyzed the long-term impacts of feeding tube placement on patients with cerebral palsy, 28% of the participants expressed problems, such as difficulty in finding respite care, restriction of mobility, changing relationship between the family and the children and missing food taste (9). In contrast, 86% of the families in another study expressed positive impacts of tube feeding on their children's care (10).

The review of the literature reveals that only one study conducted systematic review of the qualitative studies on the experiences of caregivers with feeding tube (5). However, Nelson et al. (5) found no evidence "to suggest that quality of reporting accurately reflects quality of data". Due to this reason, we believe that a systematic review of quantitative studies on the subject is essential to contribute to the literature.

The aim of this study is to identify the opinions, attitudes and experiences of caregivers of pediatric patients related with G-tube feeding. We believe that attaining this aim may help us to raise consciousness about caregivers' need from healthcare providers and to increase the positive impact of tube feeding on the lives of children and their caregivers before and after gastrostomy procedure. Such an effort may contribute to the determination of topics to be addressed in parental education, which may help caregivers to decide upon gastrostomy procedures and to cope with the difficulties in gastrostomy care.

Study Selection

We first reviewed all quantitative studies that addressed the effects of gastrostomy feeding on opinions, attitudes and experiences of caregivers or parents of pediatric patients in all countriesbefore and after gastrostomy procedure.

Inclusion and Exclusion Criteria: All quantitative studies in English, which were published onlin eup to 10 May 2015 and which were conducted on participants under the age of 18 and their caregivers, were included to the scope of the review. We excluded PhD dissertations, master theses, congress proceedings, book chapters, and studies that used both qualitative and quantitative research methods from the scope of review. Besides, studies, which were carried out by health professional other than nurses, or which were on children with gastrojejunal nutrition were excluded.

Screening the Literature

Selection of studies for review is a highly important stage in systematic review, which should be conducted to ensure credible and useful results that may provide information for health-care policy, clinical practice and future research. In consultation with JD, a clinical education librarian, two of the researchers (D.S.,

Table I: Main Concepts included in Search.

	Concepts		
Related words in Headings	**Gastrostomy** Gastrostomy Gastrostomy tubes Enteral nutrition	**Nursing** Nursing specially Nursing care Nurses Nursing role	**Caregivers** Caregiver burden Caregiver support Caregivers Family Parent Quality of life
Keywords/phrases	PEG Gastrostomy Percutaneous endoscopic gastrostomy	Nursing care Nurs(ing)	Opinion Experience Perspective View Caregiver(s) Parent(s) Family(ies)

Table II: JBI Critical Appraisal Checklist for Observational Studies(12).

Criteria	Responses			
	Yes	No	Unclear	Not Applicable
Is the study based on a random or pseudorandom sample?				
Are the criteria for inclusion in the sample clearly defined?				
Were outcomes assessed using objective criteria?				
If comparisons are being made, was there sufficient description of the groups?				
Was an appropriate statistical analysis used?				

J.D.) searched for the relevant works that were published online up to 10 May 2015 by using five electronic databases, namely CINAHL, PubMED, PSYCINFO, SCOPUS and Ovid Cochrane database of Systematic Reviews. Search strategy was decided upon the expertise of the researchers. Key searched terms were PEG, gastrostomy, percutaneous endoscopic gastrostomy, nursing care, nurs(ing), caregiver(s), parent(s), family, opinion, experience, and view (Table I). Two researchers (D.S. and D.Y.) independently evaluated article abstracts to determine the extent to which they met the inclusion criteria. Titles of articles were examined, and abstracts of potentially relevant ones were retrieved. Full-text articles that contained potentially relevant data or information were examined for eligibility. Next, two reviewers (D.S. and D.Y.) selected the articles that deserves critical evaluation from the identified citations, which were stored in EndNote X8 software.

Assessment of the Quality of Quantitative Studies

The use of critical evaluation tools parallel to the aims and design of a study and the selection of relevant questions from these tools are highly important (12). We used critical appraisal checklist for observational studies, developed by Joanna Briggs Institute (JBI) in order evaluate the quality of selected quantitative studies (Table II). Abstracts of the selected works were evaluated independently by three researchers (D.S., B.F., and D.Y.) and discussions were held in case of disagreements on classification of responses.

Result of sudies: We identified 1897 relevant citations. 29 of these 1897 citations were relevant with the research subject and eight articles met the inclusion criteria (Figure 1).

Study Characteristics

Table III describes the characteristics of the eight studies that were analyzed in this review whereas Table IV lists the types and objectives of these studies. 63% of the participants in these studies were parents (n=184) whereas 37% were caregivers (n=108). Five studies collected data after gastrostomy procedure (13-15,17,18). Whereas data was collected before and after gastrostomy procedure in the remaining three studies (19-21). Table V shows the analysis on the quality of the reviewed studies according to the JBI critical appraisal checklist for observational studies (12). The analysis reveals that no studies were based on random or pseudorandom sampling. Inclusion criteria were clearly defined in five of the studies (15,17,19-21). Objective criteria were used to assess outcomes in five studies (13,14,19-21). Five studies used questionnaires for data collection whereas scales were used in two studies and inventory was used in one study. None of the

Table III: Descriptive Characteristics and Findings of Reviewed Studies (n=8).

Study, Country	Number and type of caregivers	Number of patients (Mean and/or median and range in years)	Data Collection Method	Timing of Data Collection	Findings	Outcomes (N: Negtive, P: Positive P&N: Poitive and Neg tive)
Avistland et al. (19), Norway	44 parents	53 (Mean: 1.7; range: 0.5-14.7)	Numeric rating scale	6 months before and 18 months after inserting G-tube	Caregivers reported reduction in stress, increase in satisfaction levels of children and caregivers, and better communication between children and caregivers after receiving G-tube.	P
Buderus et al. (13), Germany	21 parents & nurses	38 (Mean: 3.86; median: 1.48)	Short questionnaire	After inserting G-tube	All of the caregivers considered the handling of the button tube as better than or equal to conventional PEG tube. Overall satisfaction was found equal (5%) or better (85%). 5% did not feel any difference whereas 10% would prefer the classic PEG-Tube.	P
Chaplen, (14), UK	16 parents	Unclear	Postal questionnaire	After inserting G-tube	56% of caregivers were not adequately prepared and were not sufficiently informed about the device before being discharged. 14% were not adequately prepared but were sufficiently informed about the device after post-education program. Using gastrostomy feeding devices contributed to the children's well-being since the device was hidden under clothing, which improves the children's body image and which eliminates the possibility of a nasogastric tube that may be traumatic for the children and their caregivers.	P&N
Matuszczak et al. (15), Poland	44 parents& caregivers	44 (Mean: 8.5; range: 0.5-1.5)	Semi structured questionnaire	After inserting G-tube	95.4% of caregivers expressed significant improvements in their own social functioning after the G-Tube replacement. 97.7% of caregivers stated a decrease in feeding times (mean from 3 hours 44 minutes to 1 hour 5 minutes). 95.4% of caregivers did not have any regrets about their consent for their children's gastrostomy. 93.1% of caregivers stated that G-Tube improved the quality of their lives significantly. However, psychosocial problems, including restricted mobility, inadequate respite care, and stress related to tube feeding, were associated with an overall negative rating of G-tube feeding. 97.7% of caregivers stated a considerable decrease in feeding times. The majority of participants expressed their satisfaction with the GT placement and improvements in their quality of life.	P&N

Sumritsopak et al. (17), Thailand	33 caregivers (25 mothers, 5 fathers, 3 others)	33 (mean: 2.4; Range: 0.9-5.29)	Telephone questionnaire or questionnaire filled at gastroenterology or patient setting	After inserting G-tube; months 4, 8 and 12	90% of caregivers strongly/somewhat expressed that they were sufficiently informed before PEG. However, 39% had difficulties in reaching a final decision about undergoing PEG insertion. 90% of caregivers expressed that they were sufficiently informed after the procedure. 31 caregivers were mostly/somewhat satisfied with the improvements in nutrition status, and 73% strongly/somewhat expressed that they spent less time on feeding via PEG.	P&N
Thorne et al. (18), USA	59 parents	62 (median: 3; range: 0.5-9.5)	Vertical visual analogue scale (Caregiver satisfaction)	After inserting G-tube	Satisfaction level of caregivers was generally high at all testing times. However, caregivers considered gastrostomy management as a major challenge to caregivers and stated that coping successfully required complex adaptive strategies, which developed over time.	P
Wilsonet al. (20), USA	Not reported	64 (19 retrospective, 45 prospective children; Range: 0.2-19.4)	Postal questionnaire, questionnaire filled at clinic	Before and after inserting G-tube	93% of caregivers expressed that their expectations about weight gain were met. Unachieved expectations included temporal G-tube use and improvements in wound healing. According to retrospective analysis, 31.5% of caregivers were satisfied, 21.1% were pleased and 47.4% were very pleased with the GT. Concerns were realized in 25%; expectations were met in 93%. Feeding time decreased following GT placement. Satisfaction was reported as satisfied (23.6%), pleased (16.4%), or very pleased (60.0%).	P
Wong et al. (21), Canada	17 caregivers	17 (median: 3; Range: 1.2-4.7)	23-items questionnaire	Before and after inserting G-tube	At the time of G-tube insertion, most caregivers were concerned with prolonged use, and possible complications associated with the use of G-tube at home. To a lesser extent, caregivers expressed their concerns about risks related to surgical procedure and cosmetic concerns. Regarding the attitudes of ten post-transplant caregivers, the study found that seven caregivers disagreed or strongly disagreed about the assertion that continuous usage of G-Tube outweighed its benefits. Five of ten caregivers expressed pressures for G-tube removal due to potential complications and to complete rehabilitation. Six caregivers considered removal of G-tube as complete rehabilitation. Nine caregivers expressed that their children's lives were not compromised by the G-tube. However, all ten caregivers considered gastrostomy as satisfactory.	P

Table IV: Objectives and Study Design of Reviewed Studies

Study	Objective	Study Design
Avistland et al, (19)	To reveal the impact of G-Tube on satisfaction levels during meals, duration of meals, oral intake, vomiting, growth and communication between children and parents	Descriptive report, before after longitudinal study
Buderus et al, (13)	To evaluate the experiences of pediatric patients with balloon gastrostomy buttons; to determine the most frequent problems after gastrostomy procedure; and, to highlight the areas for further education and studies.	Descriptive report, retrospective chart review
Chaplen, (14)	To determine the extent to which information given to the caregivers helped them to care for their children with G-Tube	Descriptive report, retrospective study
Matuszczak et al, (15)	To reveal daily functioning of caregivers and their children with G-Tube.	Descriptive report, prospective study
Sumritsopak et al, (17)	To find out the views of caregivers on percutaneous endoscopic gastrostomy	Descriptive report, A cross-sectional observational study
Thorne et al, (18)	To compare the effects of two different types of devices (skin-level and tube) on caregiver satisfaction, nutritional outcome and complications.	Descriptive report, A comparative longitudinal study
Wilson et al, (20)	To evaluate the concerns, satisfaction level and expectations of the caregivers with GT replacement in pediatric patients.	Descriptive report, A two-part retrospective and prospective study
Wong et al, (21)	To evaluate the attitudes of the patients and caregivers towards the use of G-tube in pediatric renal transplant patients.	Descriptive report, A cross-sectional observational study

Table V: Analysis of Selected works according to the JBI Critical Appraisal Checklist for Observational Studies

Study	Q1	Q2	Q3	Q4	Q5
Avistland et al, (19)	N	Y	Y	Y	Y
Buderus et al, (13)	N	N	Y	Y	Y
Chaplen, (14)	N	N	Y	Y	Y
Matuszczak et al, (15)	N	Y	N	Y	Y
Sumritsopak et al, (17)	N	Y	N	Y	Y
Thorne et al, (18)	N	U	N	Y	Y
Wilsonet al, (20)	N	Y	Y	Y	Y
Wong et al, (21)	N	Y	Y	Y	Y

Y:*Yes,* ***N:****No,* ***U:****Unclear*

studies used tools whose reliability and validity were assessed for the country that the study was conducted at. Rather, these tools were developed by the authors of the studies we reviewed by using the relevant literature.

Positive Outcomes regarding Gastrostomy Tube Feeding

Participants in five of the reviewed studies expressed how gastrostomy tube feeding improved the quality of lives of the pediatric patients and their caregivers after the procedure (13, 18-21). One of the reviewed studies found that gastrostomy tube feeding reduced stress, increased patients' and caregivers' satisfaction, and improved communication between the children and their caregivers (19). Another reviewed study found that caregivers learned how to perform tube exchange and felt safe at home or the nursing home with the procedure (13). Mobility, patient comfort at physiotherapy, parental comfort, swimming and night-time sleep were expressed as the positive effects of gastrostomy tube feeding. One of the studies reported that feeding time decreased following GT placement (20). Another study, which dealt with the attitudes of caregivers towards gastrostomy removal after renal transplantation, found that caregivers felt that benefits of gastrostomy outweighed its risks in the post-transplantation period (21).

Negative and Positive Outcomes regarding G-tube Feeding

Three of the reviewed studies found both positive and negative effects of gastrostomy tube feeding on the pediatric patients,

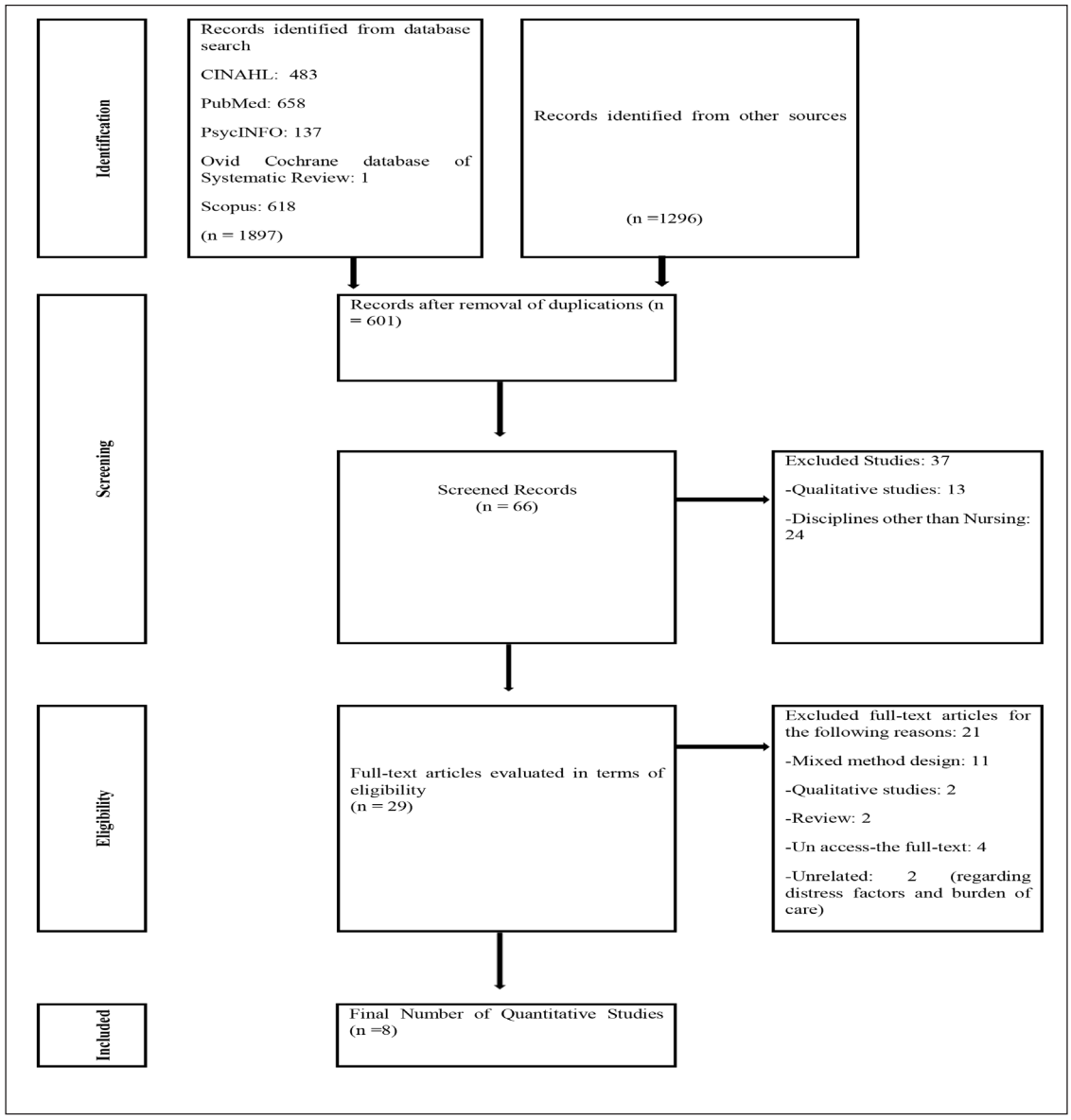

Figure 1: PRISMA flow chart detailing identification and selection of studies for inclusion

their caregivers (14,15,17). For the period before the gastrostomy procedure, these studies found that caregivers found it difficult to decide on gastrostomy procedures, and that inadequate knowledge of gastrostomy procedure was associated with a negative evaluation of tube feeding. These studies reported mobility restriction, inadequate respite care, stress related to self-feeding, inadequately prepared post-procedural education, and concerns about unintentional loss of the gastrostomy tube button, as the negative outcomes after gastrostomy procedure. In one of the studies, 44% of the parents expressed that they were not adequately prepared for gastrostomy tube placement whereas 86% of the parents stated that they felt prepared and received adequate post-procedural education on the use of device (14). In another study, although nearly all the caregivers (95.4%) reported significant improvements in their social functions after the placement of G-Tube, the remaining 4.6% of the participants considered G-Tube as an additional disability and gave negative responses to recommendations for G-Tube placement (15). A third study found that 39% of the caregivers found it difficult to decide on gastrostomy procedure though most of the participants (90%) expressed that they were sufficiently informed about G-Tube placement (17).

G-Tube placement and feeding have physical, emotional and relational challenges and benefits for the pediatric patients and their families. Informing the caregivers about the potential outcomes of G-Tube may contribute to efforts to raise consciousness about caregivers' need for support from healthcare providers. Besides, it may increase the positive effects of tube feeding on the lives of the children and their caregivers before and after gastrostomy procedure. This systematic review dealt with the findings of eight quantitative studies on the opinions, attitudes and experiences of caregivers

of pediatric patients related with G-Tube feeding. The findings were classified into two the groups of positive outcomes and negative & positive outcomes regarding G-Tube feeding. Similarly, systematic review of qualitative studies on the subject by Nelson et al. found five studies that found a balance between positive and negative outcomes of G-tube feeding (5).

Analysis of the quality of the quantitative studies by using JBI Critical Appraisal Checklist reveals that 65% of the responses to the questions in checklist were 'yes', 32.5% were 'no' and 2.5%, were 'unclear'. None of the reviewed studies were based on random or pseudorandom sampling. One of the limitations is that most of the studies did not clearly state whether the caregiver or the parent was the mother, father or another member of the family of pediatric patients (13-15,18-21). Due to this reason, the results may not be applicable to all family members. We believe that such studies should report whether the caregivers are the mothers, fathers or other family members of the children. We are also aware of potential recall bias and of the fact that the relatively small size of participants may limit robust statistical analyses and generalizability (13-15,18-21).

Decreased stress levels increased satisfaction levels of the pediatric children and their caregivers improved communication between the children and their caregivers during the meals, caregivers' comfort with higher night-time sleep, and sense of confidence with the procedure at home or in the nursing house are the common positive outcomes reported by the studies (13, 18-21). One of the systematic reviews of the qualitative studies also found parallel positive outcomes (5). This positive outcomes regarding G-Tube feeding should be taken by healthcare professionals into account when informing the caregivers before the gastrostomy procedure.

Caregivers' complaints about being inadequately informed associated with an overall negative consideration of G-Tube feeding were the common negative outcomes for taking decisions on gastrostomy procedure (14). Therefore, healthcare providers should be aware of the caregivers' negative opinions on G-Tube feeding in order to assist in preoperative counseling.

CONCLUSION

This systematic review aimed to investigate the opinions, attitudes and experiences of the caregivers on G-tube feeding in order to raise consciousness about caregivers' need for support from healthcare providers and to improve the impact of G-tube feeding on the lives of children and caregivers before and after gastrostomy procedure. With this aim, we synthesized the results of eight quantitative studies that analyzed the positive and negative outcomes related with pediatric patients, and caregivers before and after gastrostomy procedure. Three studies we analyzed found various advantages of gastrostomy procedure, including increase in weight, decrease in respiratory infection, and improvements in the children's and caregivers' quality of life. However, five studies noted both negative and positive outcomes before and after gastrostomy procedure. Therefore, healthcare providers should inform the patients and their caregivers about all aspects of the procedure and the possible negative and positive outcomes in order to help the caregivers to make the final decision on gastrostomy procedure for the children.

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