FEEDING DIFFICULTIES IN CHILDREN WITH FAILURE TO THRIVE (FTT): AWARENESS OF CHARACTERISTICS OF FTT IN URBAN & RURAL MOTHERS / FEMALE CAREGIVERS

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Abstract

*Failure to thrive (FTT) is a medical condition*http://en.wikipedia.org/wiki/Failure_to_thrive - cite_note-0 *which may also affect the development of communication skills in children. The study aimed to investigate the awareness level of diagnostic and rehabilitation facilities of children with FTT among the mothers/ female caregivers of their children. Two questionnaires were prepared and administered on 14 urban and 17 rural mothers/ female caregivers of children with FTT. Analysis of their responses revealed that the rural and urban mothers/ female caregivers seemed to be aware of those features in FTT which were more overt/ easily noticeable. A significant result obtained was that only one mother was aware of the term FTT. It is concluded that awareness of FTT management in both urban and rural mothers/ female caregivers is lacking significantly. The rural mothers/ female caregivers need to be sensitized on issues related to feeding as this can lead to inadequate nutrition and therefore FTT. This should be included as a routine part of the newborn screening program.*

Key words: *Failure to thrive, Feeding, Questionnaire, Awareness, Urban/rural*

Failure to thrive (FTT) is a medical termhttp://en.wikipedia.org/wiki/Failure_to_thrive - cite_note-0 which denotes poor weight gain and physical growth failure over an extended period of time in infancy and does not imply any abnormal intellectual, social, or emotional development. FTT includes characteristics such as reduced weight which is consistently below 3rd to 5th percentile for a given age and/ or progressive decrease in weight to below 3rd to 5th percentile for a given age and/ or a decrease in the percentile rank of two major growth parameters of poor weight gain and physical growth failure in a short period (Bithoney, Dubowitz, & Egan, 1992).

The cause of FTT could be any identified medical condition (organic) or related to environmental factors (nonorganic). Irrespective of the cause, the symptoms relate to inadequate nutrition. Some of the common etiologies of FTT are delayed physical growth and cognitive development (Kristiansson, & Fallstrom, 1987; Corbett, Drewett, & Wright, 1996). Many children also present mixed etiologies such as a medical disorder, family stress (poor parent child relationship, psychosocial factors in mother and others) (Gahagan, & Holmes, 1998). The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (2000), describes several psychological conditions in infants and children suffering from FTT. According to this classification, the term 'Reactive Attachment Disorder of Infancy or Early Childhood' is used to describe the psychological damage caused by extreme emotional neglect. Either of the two extremes of parental attention (neglect or hypervigilance) can lead to this condition. The stress can compound the feeding problem and aggravate FTT. Abnormal pathophysiology such as inadequate caloric intake, inadequate absorption, excess metabolic demand, or defective utilization is also cited under etiology.

The severity of a child's under-nutrition/ malnutrition can be determined most easily by using the 'Gomez' criteria in which the child's current weight for age is compared with the expected weight (50th percentile) at that age. FTT is considered severe if the weight is less than 60 percent of expected, moderate if the weight is 61 to 75 percent of the expected and mild if the weight is 76 to 90 percent of the expected (Powell, 1988). Diagnosis and intervention carried out in time helps preventing malnutrition, developmental delays and other sequels of FTT. A thorough client history is the best guide to establish the etiology of FTT, in deciding the direction of further evaluation and management. All children with failure to thrive need additional calories for catch-up growth (typically 150 percent of the caloric requirement for their expected and not actual weight). Few need laboratory investigation to ascertain the cause. Hospitalization is rarely required and is indicated only for clients with severe degree of FTT whose safety is a concern. A multidisciplinary approach is recommended when FTT persists despite intervention or when it is severe (Casey, Wortham, & Nelson, 1984; Morice-Trejos, Jiménez-Soto, Fonseca-Fallas, & Alfaro-Mora, 1989; Schmitt, & Mauro, 1989; Lopez, & Schumann, 1997). Traditionally, a multidisciplinary team for FTT management includes physicians, nurses, dietitians, social workers, and psychologists (Maggioni, & Lifshitz, 1995).

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Children with FTT are more often reported to be at risk for adverse outcomes such as short stature, behavior problems, and developmental delays (Oates, Peacock, & Forrest, 1985; Kristiansson, & Fallstrom, 1987; Heffer, & Kelley, 1994; Corbett, Drewett, & Wright, 1996; Gahagan, & Holmes, 1998; Metallinos-Katsaras & Gorman, 1999). There is limited number of studies on children with FTT, each with different definitions and designs, rendering it difficult to comment with certainty on the long-term results of FTT (Drotar, & Robinson, 1999). In addition, it is often difficult to disentangle the effects of FTT from those of the high-risk environments in which FTT often occurs (e.g., poverty, high family stress, and poor parental coping skills) (Gahagan, & Holmes, 1998; Sherry, 1999). To decrease the risk of adverse effects, it is important to recognize and treat FTT as early as possible.

Ascertaining the child's developmental status at the time of diagnosis is important because children with FTT are reported to have a higher incidence of developmental delays than the general population (Rider, & Bithoney, 1999). A complete physical examination is essential to rule out: (1) dysmorphic features suggestive of a genetic disorder impeding growth; (2) underlying disease that may impair growth; (3) factors related to child abuse; and (4) effects of malnutrition (Wissow, 1990; Rider, & Bithoney, 1999).

There is no study known to the investigator that addresses the FTT condition in Indian population and relates it to the area of communication disorders. This study attempts to address the mothers or female caregivers of potential children with the condition of FTT with varying communication disorders with respect to their knowledge about the condition of FTT, its characteristics, identification and management.

Early childhood is a critical period for growth and development, and early intervention for any child with FTT will maximize the potential for better outcomes (Metallinos-Katsaras, & Gorman, 1999). Ignorance and unawareness of such a critical and important factor in the child health care may lead to irreversible, irreparable damages to the child's body and mind. FTT being a condition which presents a number of concomitant associated problems is likely to stimulate the interest for a speech- language pathologist because communication impairment in a child could have its root in the general health of the child. Any deprivation in feeding and related issues reflects on the development of various milestones such as physical, social / adaptive and speech language skills. Since FTT can lead to risk in communication development, it should be listed as one of the prime areas of focus in the routine clinical practice of a speech language pathologist. However, the current trend in clinical practices of speech- language pathologists in India gives no scope for focused attention on dysphagia management in general. It is natural then to expect that FTT as a condition is quite often ignored although it is known to present risk for acquisition of speech and language skills of children. Among children with communication disorders, those who have cerebral palsy, severe grade mental retardation , pervasive developmental disorders, seizure disorders and other developmental delays are more likely to present symptoms of FTT (Oates, Peacock, & Forrest, 1985; Morice-Trejos, Jiménez-Soto, Fonseca-Fallas, & Alfaro-Mora, 1989). In this study a specific checklist was compiled to check if awareness of FTT differed in urban and rural mothers/ female caregivers in terms of their knowledge on various aspects of FTT.

Clinical implication of FTT as a co-morbid or associated problem existing with any other medical/ non medical condition including that of communication disorders is not an area which is much explored. FTT as an independent or associated condition is a very important clinical issue in India because of increased susceptibility of children to conditions such as poverty, malnutrition and infections, poor living conditions and unhygienic practices, atleast in some parts of the population. Levels of literacy have a major influence on the lifestyle of any population. Literacy level of women in India, though has improved to a considerable extent, is yet to reach an optimum level (The National Literacy Commission Census, 2001). This study included mothers/ female caregivers as participants as they spend more time with their children. The study attempted to understand the level of mothers'/ female caregivers' awareness of the causes, characteristics, diagnosis and management of FTT.

Aims of the study

To investigate the awareness level of urban and rural mothers/ female caregivers of children with various communication disorders such as cerebral palsy, mental retardation, pervasive developmental disorders and the multiple disabled with respect to:

- The characteristics of FTT
- Procedures/ methods used in the coping/ management of FTT.

Method

The study was conducted in three phases:

Phase 1: Preparation of the questionnaire for gathering information on feeding difficulties.

Since no standard questionnaire on FTT was

available, two questionnaires were prepared by the investigators compiling the questions and test domains addressed by Meerapriya (2009), Banumathy (2008) and Vani (2008) in their individual studies. The first one was a close ended questionnaire that was framed in English based on literature survey and reported clinical studies. Each question carried a close ended option as "Yes" or "No". Questionnaire on Clinical Characteristics of FTT is provided in APPENDIX A. The questions incorporated in this questionnaire included the following domains:

1) Oral Mechanism Examination. This was included as a screening measure to rule out any structural inadequacy and not functional adequacy.
2) General history of the client related to feeding:
   a. Medical and related
   b. Behavioral and related
3) History related to oral motor abilities and
4) Specific issues with respect to feeding and related information.

The second questionnaire was prepared to assess awareness of diagnostic issues & rehabilitation of FTT amongst the mother's/ female caregivers. This section included 22 questions in English to tap the awareness of mothers / female caregivers regarding issues related to identification, management, nutritional modifications required and referrals for their words. The structure and content of this questionnaire is shown in APPENDIX B.

Phase 2: Administration of the questionnaires (Appendices A & B) on parents of children with communication disorders.

Participants in the study:

The study included 31 mothers / female caregivers of children with communication disorders below the age of 12 years (Table 1). Care givers on this clinical population was selected as the literature reports a higher prevalence of FTT in them (Oates, Peacock, & Forrest, 1985; Morice-Trejos, Jiménez-Soto, Fonseca-Fallas, & Alfaro-Mora, 1989). Only mothers / female caregivers were included as majority of children availing clinical services at the place of study were accompanied by mothers / female caregivers. The criteria for the selection of mothers / female caregivers as participants were based on their children as follows:

- Children should present with communication disorders such as cerebral palsy, mental retardation, pervasive developmental disorders and multiple disabilities as diagnosed by an experienced speech language pathologist. The severity of the condition was not considered as a variable.

Table 1: *Distribution of children with respect to sex and disorder*

Disorder in the children of mothers/female caregivers	Children of the mother/female caregivers						Total
	Urban			Rural			
	Male	Female	Total	Male	Female	Total	
Cerebral Palsy	1	2	3	1	3	4	7
Mental retardation	2	2	4	3	2	5	9
Pervasive developmental disorder	3	-	3	2	1	3	6
Multiple disability	2	2	4	2	3	5	9

- Children should present feeding and related problems of any degree, which has affected the normal feeding pattern of the child in terms of quantity or quality of intake.
- Children should not be suffering from any other serious medical conditions that might affect the ability to thrive.

The criteria for the classification of mothers/ female caregivers under the urban and rural category were based on a checklist including the following factors which was administered by the principal investigator.

- Information on socio- economic status and overall standard of living
- If they were living in a town or city
- If she was literate and is willing to educate children too.
- If the town/ city in which she lives runs on electricity, has conveniences for tap water and if sanitary facilities are present.
- If the family lives near a high density of human-created structures and resident people
- If the city/ town has advanced civic amenities, opportunities for education, facilities for transport, business and social interaction
- If the family receives the benefits of man's advancements in the areas of science and technology
- If the family is not dependent on the environment for their day to day functions, well being and work.
- If businesses in the city/ town stay open late into the evenings

- If the city/ town has traffic and pollution problems

Mothers/ female caregivers who answered positively to most of the questions were classified as urban and those who did not were classified as rural. There were a total of 14 urban mothers/ female caregivers and 17 rural mothers/ female caregivers.

Procedure:

The mothers/ female caregivers were given the questionnaire individually and were asked to answer each question on the questionnaire as "yes" or "no". In case of rural mothers/ female caregivers (illiterates/ semi literates), clinician who provided speech- language therapy for their children and who spoke the native language of the family assisted them to answer the checklist. The clinician asked the questions in their respective native language.

Phase 3: Analysis of the responses to the two questionnaires.

A score of '1' was assigned to a question which was answered in favor of awareness and '0' for those questions answered not in favor of awareness. The total scores obtained by each participant were computed and the group total and mean scores were derived. The raw scores were converted to percentage score to facilitate comparison of the performance of the mothers / female caregivers to the various subsections of the two questionnaires. The data was treated with suitable statistical procedures.

Results and discussion

The results are discussed under two sections:

1. Comparison of awareness level of the characteristics of FTT in urban and rural mothers/ female caregivers of children with various communication disorders: cerebral palsy, mental retardation, pervasive developmental disorders and the multiple disabled.
2. Comparison of awareness level of procedures/ methods used in the coping/ management of FTT in children across the urban and rural mothers/ female caregivers of children with various communication disorders: cerebral palsy, mental retardation, pervasive developmental disorders and the multiple disabled.

Section 1: *Comparison of awareness level of the characteristics of FTT in urban and rural mothers/ female caregivers of children with various communication disorders: cerebral palsy, mental retardation, pervasive developmental disorders and the multiple disabled.*

Table 2 shows the comparison of mean percentage responses of mothers/ female caregivers from rural (N=17) and urban (N=14) groups on the different sections of the questionnaire. The results provided in Table II shows that the mothers/ female caregivers of children with cerebral palsy who came from an urban background were better aware of the oral motor abilities [urban (mean, standard deviation =28.21, 4.44); rural (mean, standard deviation= 21.15, 4.97)] and feeding issues [urban (mean, standard deviation= 18.70, 2.49); rural (mean, standard deviation=15.47, 5.71)] than their rural counterparts. Higher scores on general history was more evident in the rural population of children with cerebral palsy [urban (mean, standard deviation= 8.63, 2.96); rural (mean, standard deviation= 9.71, 3.51)]. This could imply that the rural mothers were more aware of factors related to general history of their children's condition than specific issues related to feeding and oral motor abilities of their children.

In comparison the trend was different for awareness levels of characteristics of FTT in mothers/ female caregivers of children with mental retardation when compared to that of children with cerebral palsy. There were more positive answers for questions on oral motor abilities in the rural population [urban (mean, standard deviation= 26.92, 8.88); rural (mean, standard deviation= 33.85, 3.22)]. There were also more positive answers for questions on general history in the rural population [urban (mean, standard deviation= 6.76, 2.94); rural (mean, standard deviation= 9.18, 3.37)]. Feeding issues follow a similar trend as that of cerebral palsy with more positive answers for the urban population.

The trend observed for children with pervasive developmental disorders was different from that followed in the two clinical populations of cerebral palsy and mental retardation. Here, awareness for aspects of general history in the urban population was more than the rural [urban (mean, standard deviation= 11.76, 5.13); rural (mean, standard deviation= 9.02, 3.60)] where as issues on feeding [urban (mean, standard deviation= 8.87, 1.50); rural (mean, standard deviation= 13.19, 1.50)] received a higher score in rural when compared to urban. For oral motor abilities, the urban groups had poorer scores than the rural [urban (mean, standard deviation=16.67, 5.88); rural (mean, standard deviation= 21.79, 2.22)].

Table 2: *Mean and standard deviation of urban and rural children with CP, MR, PDD and MD to the different sections in the questionnaire.*

Categories of questions		CP	MR	PDD	MD
GH	Urban	8.63 (2.96)	6.76 (2.94)	11.76 (5.13)	5.59 (1.76)
	Rural	9.71 (3.51)	9.18 (3.37)	9.02 (3.60)	7.29 (4.66)
OMA	Urban	28.21 (4.44)	26.92 8.88)	16.67 (5.88)	35.58 (5.77)
	Rural	21.15 (4.97)	33.85 (3.22)	21.79 (2.22)	27.69(13.16)
FDG	Urban	18.70 (2.49)	15.47 2.66)	8.87 (1.50)	21.40 (4.41)
	Rural	15.47 (5.71)	14.10 3.12)	13.19 (1.50)	13.673.60)

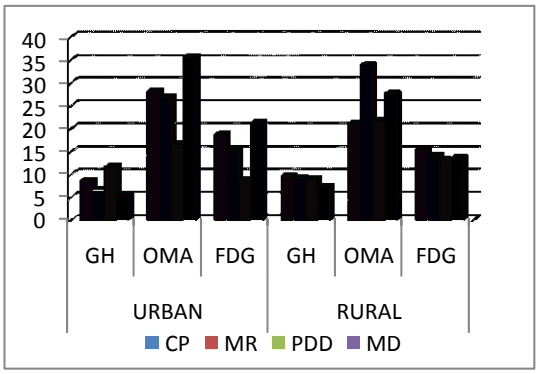

Figure 1: *Mean and standard deviation of urban and rural children with CP, MR, PDD and MD to the different sections in the questionnaire.*

**Note: CP= Cerebral palsy, MR= Mental Retardation, PDD= Pervasive Developmental Disorders, MD= Multiple Disabled, GH= General History, OMA= Oral Motor Abilities, FDG= Feeding*

The group of mothers / female caregivers of children with multiple disabilities followed a similar trend as that of cerebral palsy with more awareness for general history in the rural population [urban (mean, standard deviation= 5.59, 1.76); rural (mean, standard deviation= 7.29, 4.66)], whereas oral motor abilities [urban (mean, standard deviation= 35.58, 5.77); rural (mean, standard deviation= 27.69, 13.16] and feeding issues [urban (mean, standard deviation= 21.40, 4.41); rural (mean, standard deviation= 13.67, 3.60)] being more prominent in the urban population.

The points of interest as gathered from Table 2 and Figure 1 is that the groups of mothers/ female caregivers of cerebral palsy and multiple disability groups both show a similar trend whereas those of children with mental retardation and pervasive developmental disorder groups both show different trends. On the whole it is evident that the urban population had more positive awareness on aspects of oral motor abilities [urban (mean, standard deviation= 27.47, 9.03); rural (mean, standard deviation= 26.9, 8.92)] and feeding issues [urban (mean, standard deviation= 16.44, 5.45); rural (mean, standard deviation= 14.13, 3.57)]. On the other hand the rural mothers/ female caregivers were better aware of aspects related to general history than the urban population [urban (mean, standard deviation= 7.89, 3.70); rural (mean, standard deviation= 8.72, 3.63)].

Rural population may be more susceptible to different medical, psychological and socio-economic factors than the urban population. The lack of awareness and sometimes their ignorance may lead to various problem behaviors in their children. Their belief of bearing more number of children, more hands for work and more earning for the family may put the mother onto risk of malnutrition during pregnancy with lack of sufficient food for the entire family.

This may lead to complications during delivery and adversely affect the new born. The serious complications and even mild ones may put an infant to the category of failure to thrive. Also, as the number of members of a family increases, there is less individual attention and interaction given to each child. This also is a recognized cause of FTT as reported in the literature (Wissow, 1990).

Cerebral palsy children are known to have feeding difficulties. The severity of this condition varies with the extent of brain damage. The feeding difficulties put them into the high risk category of FTT. As reported in the literature, FTT may lead to developmental delays in both motor and communication domains (Metallinos-Katsaras & Gorman, 1999).

The mother/ female caregivers of pervasive developmental disorders group had a more clear awareness of the factors relating to general history of the child in the urban population. This calls for attention of the speech language pathologists to collect a careful and detailed history from this population. Also, it is seen that children with mental retardation have more issues with oral motor difficulties than feeding issues and history in the rural population.

From the results of this study it seems like the mothers or female caregivers know the important details of their children with respect to general history and oral motor abilities. It is probable that from mothers' point of view these are most

evident and easily noticeable features in their children's disorders, because of the associated symptoms and medical issues that have always caught their attention. Compared to the other sections of feeding and oral motor abilities, general history may have more scope for obtaining relevant information from parents. The lesser awareness for oral motor issues could probably be due to the fine nature of these movements which in turn receive very little attention from the parents. Feeding problems as is known is a problem by itself or may be associated with other conditions.

Despite the different trends seen in the responses of the mothers / female caregivers of different clinical groups such as Cerebral Palsy, Mental Retardation, Pervasive developmental disorders and Multiple disabilities, the scores clearly point to the existence of FTT as a factor in each of these client groups. Thus the factors that lead to FTT should be carefully observed and brought under control by the professionals dealing with this clientele. Though identification of FTT is primarily recognized as the domain of a pediatrician, suspected cases can be screened over similar questionnaires and appropriate referrals can be made by any professional.

The sensitivity of the questionnaire is established as different trends were evident among the responses of mothers/ female caregivers of different clinical populations. Thus, it may be assumed that similar questionnaires with a detailed probe into the various suspicious domains of FTT are good enough to be used with the clinical population for further testing and assessments. Questionnaires have the advantage of being user friendly and can be self rated if needed. This may save time of the professional and also avoid unnecessary/ unavoidable comments and questions that may evoke feeling of guilt if asked in a direct interview session.

When it is a problem by itself, it receives more attention than otherwise. When it exists as an associated problem, feeding is believed to get better with alleviation of symptoms of the primary disease and may go unmanaged for a long time. Thus, the mothers or the female caregivers form a very important part of the rehabilitation team. A questionnaire filled by them can be highly reliable than any other source of information. They are the individuals who spend most of their time with the child and observe every behavior of the infant. Another point of emerging interest is that the rural or urban mothers and caregivers did not differ significantly in this aspect. They still remained as the most reliable sources as they provided valuable information about the various domains screened for FTT.

Section 2: *Comparison of awareness level of procedures/ methods used in the coping/ management of FTT in children across the urban and rural mothers/ female caregivers of children with various communication disorders: cerebral palsy, mental retardation, pervasive developmental disorders and the multiple disabled.*

From the responses of the mothers / female caregivers in this section, it was evident that very few mothers/female caregivers of children with communication disorders knew about the term 'Failure To Thrive' and about the methods to cope or manage with this condition. There was only 1 mother who answered positively for awareness of FTT and its coping strategies out of the 31 others mothers/ female caregivers who participated in this study. This mother belonged to the highly literate urban population group and she was exposed to this concept as she resided abroad for a significant long time.

Urban population is more educated and more financially well placed compared to the rural population (The National Literacy Commission Census, 2001). Awareness of different existing clinical conditions, literacy and education and increased facilities keep the urban population vigilant to such conditions. An early identification and management puts the urban population on a better stand than rural population.

FTT is identified as a very important factor and that which is given immediate attention in the western countries. Organic FTT is given immediate medical help and non organic FTT's are identified at the earliest and appropriate measures are taken. The lack of awareness of this condition in India puts a large number of our newborns at risk especially when our country is more susceptible to the causes of FTT due to the social and economic conditions of different sectors of our population. The number of professionals who are aware and aim to identify and diagnose this condition is not known.

Though many of them know about the problems and complications of feeding problems, the management of these is neglected due to limited awareness. This puts a larger number of infants into risk. Thus, creating awareness about FTT can be a major initial step in any speech-language therapy clinic. This should be done through education of parents and through proper counseling. This should be made a routine part of the newborn screening. Awareness should be created among professionals about the early identification and management options available

to them. This knowledge is expected to be low in India. Feeding problems cannot be managed only by the family. The underlying cause of these problems should be dealt with proper professional guidance such as from a pediatrician. Although it is beyond the scope of this study as a future direction of interest it would be worth understanding the awareness level of FTT as a important clinical entity even within the medical fraternity other than pediatrician who do not directly deal with the physical growth of the child and rehabilitation specialists such as speech- language pathologists, occupational therapists, physiotherapists etc.

Conclusions

The results point to an urgent need to include 'Failure to Thrive' assessment and identification at an early stage in infants and children. This may help the professionals involved in the primary prevention of FTT in the clinical conditions such as cerebral palsy, pervasive developmental disorders, mental retardation and multiple disabilities. Though these conditions cannot be prevented by controlling the causes of FTT, the associated problems that may hamper the progress of the child because of existence of FTT in a child can be brought into control by controlling this condition. Also, there is a need to know more about the status of FTT in India. More awareness should be created among the common men and also the professionals who form a rehabilitation team to help those children with communication disorders. There should be a greater emphasis to include questions about feeding in the general interview to collect the history of the client. Counseling the new mother or prospective mothers on this condition will help us bring a large number of conditions under control.

Implications

This study addressed an area that has been scarcely researched from the communication rehabilitations point of view. The questionnaire prepared in identifying children with FTT was sensitive as it identified significant differences across the urban and rural population interviewed for the study. The different responses provided by mothers / female caregivers of different clinical groups throw light on the differential awareness level regarding various issues related to feeding in general and FTT in specific.

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Appendix A

Questionnaire on clinical characteristics of children with Failure To Thrive (FTT)

(*Note:* The caretakers or the clinician can fill up the details in this part of the questionnaire. In illiterate group of clients, this part of the information will be entered by the clinician after reviewing the medical reports of the clients if available)

A] Oral mechanism examination (structural and functional adequacy)
[Adopted from Meerapriya (2009) and Banumathy (2008)]

Structure	Appearance	Movement
Lips	• Normal • Cleft (repaired / unrepaired) • Deviated • Scar	Observe for symmetry / asymmetry during ➢ Retraction ➢ Protrusion • Overall function of lips: ➢ Normal ➢ Abnormal
Teeth	• Normal • Missing • Supernumerary • Overbite • Underbite • Cross bite • Others	--
Jaw	• Micrognathia • Macrognathia • Occlusion defects ➢ Neutrocclusion ➢ Distocclusion ➢ Mesiocclusion	Observe for the following during opening and closing: ➢ Symmetrical ➢ Asymmetrical ➢ Exaggerated & jerky ➢ Slow and laborious • Deviations to Lt / Rt
Tongue	• Normal • Microglossia • Macroglossia • Tongue tie • Fissured	Observe if normal or abnormal during: • Elevation (front and back) • Retraction • Protrusion • Lateral movements • Retroflexion
Hard Palate	• Normal • Cleft (Repaired / Unrepaired) • Fistula • Arched (High / Low)	--
Soft Palate	• Normal • Cleft (Repaired / Unrepaired / Submucous) • Short	On phonation observe for elevation of the soft palate. Record if it is: • Symmetrical • Asymmetrical • Deviated to Rt / Lt

Uvula	• Normal • Absent • Cleft (Repaired / Unrepaired) • Bifid • Elongated	--	
Nose	• Normal • Abnormal	--	

B] General history of the client related to feeding

Sl. No.	*Items*	*Yes*	*No*
	Medical and related		
1.	Does the child / your child have any of the following endocrinal abnormalities: • Hypothyroidism • Hyperthyroidism • Diabetes • Growth hormone deficiency • Cretinism • Pituitary tumors • Genital abnormalities with glandular dysfunctions • Any other		
2.	Does the child / your child have any of the following Gastrointestinal disorders: • Gastroesophageal reflux • Celiac disease • Milk protein allergy • Pancreatic insufficiency • Inflammatory bowel disease • Pyloric stenosis • Any other		
3.	Does the child / your child suffer from any of the following cardiac disorders: • Congestive heart failure • Congenital anomalies of heart • Murmur • Any other		
4.	Does the child / your child suffer from any of the following pulmonary disorders: • Brochopulmonary dysplasia • Asthma • Cystic fibrosis • Any other		
5.	Does the child / your child suffer from any of the following infectious diseases: • HIV • Parasitic infections • Tuberculosis • Any other		
6.	Does the child / your child suffer from any of the following metabolic disorders: • Galactosemia • Methylmalonic academia • Tyrosinemia • Any other		
7.	Does the child / your child suffer from any of the following renal disorders: • Renal tubular acidosis • Chronic urinary tract infections • Chronic renal insufficiency • Any other		
8.	Does the child / your child suffer from any of the following syndromes: • Down syndrome • Turner syndrome • Russell-Silver dwarfism • Fetal alcohol syndrome • Any other		
9.	Does the child / your child present abnormalities in the bowel movements: • Number of times of stool passage • Quality of stool		

- Any other

10. Does the child / your child present abnormalities in passage of urine:
    - Number of times of urination
    - Quality of Urine (E.g., Foul smell etc)
    - Any other
11. Does the child / your child have following breathing problems:
    - Short breath
    - Rapid breathing
    - Abnormal or erratic breathing rate
    - Noisy breathing/ Stridor
    - Wheezing / Crackles
    - Any other
12. Does the child / your child have a history of one or multiple episodes of pneumonia?
13. Was the child hospitalized for breathing related problems in the past?
14. Does the child / your child have a positive history of:
    - Medical illness/es
    - Surgery/ies
15. Does the child / your child have abdominal lumps / masses / growths?
16. Does the child / your child have / present any of the following:
    - Persistent diaper rash
    - Skin bruising
    - Unexplained scars in the genital area
    - Any other
17. Does the child / your child have skin rashes on the:
    - Face
    - Lips
    - Other parts of the body
    - Any other
18. Does / Did the child / your child have yellowish discoloration of skin/ jaundice?
    - At birth
    - After birth
    - After 3 months (specify)
19. Was the child / your child exposed to / suffer from any of the following types of poisoning:
    - Lead poisoning
    - Manganese poisoning
    - Any other

Behavioral and related

20. Does the child / your child have normal mental abilities?
21. Does the child / your child have poor poor eye contact?
22. Does the child / your child have poor poor attention span?
23. Does the child / your child exhibit any of the following behavioral problems:
    - Head banging
    - Temper tantrums
    - Aggression
    - Repetitive rocking of the body
    - Any other
24. Does the child / your child present overactivity / hyperactivity?
25. Does the child / your child show poor social interaction skills such as lack of smile, lack of interest in environment?
26. Does the child / your child present history of snoring or stops breathing when sleeping?
27. Does the child / your child show signs of irritability, distractibility?
28. Does the child / your child bite him/herself or others?
29. Does the child / your child constantly put things into his/her mouth?
30. Does the child want to taste everything, including any non food items?

C] History related to oral motor abilities
[Adopted from Meerapriya (2009) and Vani (2008)]

Sl. No.	*Items*	*Yes*	*No*
1.	Does the child / your child present chewing difficulty?		
2.	Does the child / your child present oral/ nasal regurgitation? (swallowed food comes out of nose or mouth)		
3.	Does the child / your child present drooling? (saliva out of mouth)		

4. Does the child / your child have uneven teeth with respect to size, shape and position?
5. Does the child / your child present any of the following:
   - Weakness in the oral muscles
   - Slow oral movements
   - Incoordinated movements of the oral structures
   - Facial/lingual asymmetry
   - Paralysis or paresis of tongue/ lips /jaw
   - Any other
6. Does the child / your child have poor lip seal due to any of the following:
   - Paralysis or paresis of lips
   - Macrolabia
   - Drooling
   - Jaw drop (Hypotonia in the lower jaw)
   - Scars in the lips
   - Injury in the lips
   - Any other
7. When touched on face/cheeks/lips, does the child / your child show:
   - Insensitivity to touch
   - Oversensitivity to touch
   - Discomfort
   - Avoidance
   - Any other
8. Does the child / your child present a history of delay or deviancy in acquiring the following oral skills:
   - Biting
   - Chewing
   - Swallowing
   - Blowing

D] Specific issues with respect to feeding and related information

Sl. No.	*Items*	*Yes*	*No*
1.	Does the child / your child show abnormal food preferences?		
2.	Does the child / your child have food allergies/ bad reactions to some foods?		
3.	Does the child / your child refuse to eat and/or drink?		
4.	Does the child / your child prefer not being fed by you? (parents)		
5.	Does the child / your child not demonstrate clear signs of the following: • Cues the caregiver, including interaction through vocalization and smiles • Cues for need for a break or rest. • Opens the mouth in anticipation of food • Stop crying when the caregiver attempts to sooth • Display of some tension at beginning of feeding and decrease in tension once feeding has begun • Show periods of alertness during the feeding • Respond to the caregiver's attempts to communicate and interact • Look in the direction of the caregiver's face then the caregiver talks • Mold into the contours of the caregiver's body • Suck and make feeding sounds following feeding attempts by the caregiver		
6.	Does the child / your child demonstrate any of the following during feeding session? • Irritability • Crying • Frenzy • Inconsolability • Rapid changes in emotional state • Restlessness • Drowsy • Strained alertness • Panicked alertness • Hyper alertness • Diffuse sleep or awake states • Staring • Frequent gaze aversion		

- Strained fussing or crying
- Silent crying

7. Does the child / your child show any of the following motor signs?
   - Flaccidity in trunk, extremities and / or face.
   - Hypertonicity in trunk, extremities and/or face.
   - Hyperextension of the legs
   - Hyperextension of the arms and hands
   - Arching the body as a whole
   - Fisting
   - Increased facial grimaces
   - Frantic, diffuse activity of the extremities
   - Frequent twitching of the body parts
8. As a parent / caregiver do you not attend to the following signs given by your child during feeding?
   - Respond in a contingent manner to the child's cues
   - Sooth or quiet a distressed infant
   - Demonstrate warmth and affection towards the child communicate a positive feeling tone
   - Foster cognitive growth through touch, movement, and talking
   - Delay stimulating or responding until the infant signals readiness
9. Does the child / your child show the following signs of stress in feeding when being fed by the parent / caregiver?

   Signs of moderate Stress:
   - Sighing
   - Yawning
   - Sneezing
   - Sweating
   - Hiccupping
   - Tremoring
   - Startling
   - Gasping
   - Straining

   Signs of major stress:
   - Frequent or prolonged coughing
   - Spitting up
   - Gagging
   - Choking
   - Color changes (Cyanosis - blueness of skin)
   - Respiratory pauses
   - Irregular respirations
10. Does the child / your child have trouble handling liquids more than the solids?
11. Is the child / your child a messy eater, that is, he/she frequently spills during feeding?
12. Is the child / your child not able to:
    - Hold straw with lips
    - Grasp cup with lips
    - Suck liquid with lips
    - Chew the food
    - Clear the residual food in the mouth using tongue movements
13. Does the child / your child have a limited food selection in terms of taste?

    Eats only particular foods:
    - Hot
    - Cold
    - Sweet
    - Sour
    - Salty
    - Spicy
    - Bitter
14. Does the child / your child have a limited food selection?

    Eats only particular foods:
    - Soft

- Semi solid
- Thin liquid
- Thick liquid
- Crunchy
- Spicy
- Hard

15. Does the child / your child show:
    - Poor appetite during feeding
    - Fussy while feeding
    - Bored/disinterested while eating
16. During feeding, does food get stuck in between the child's / your child's teeth?
17. During feeding, does the child / your child take:
    - Longer time to feed
    - Less quantity of food in a given time
18. Does the child / your child cough:
    - During feeding
    - After feeding
19. If the child is being breast fed, is the lip seal of the child inadequate on the nipple?
20. If the child is bottle fed, is the suck-swallow breathing rhythmic pattern inadequate?
21. Does the child / your child not show vertical munching movements even for easily dissolvable solids?
22. Does the child / your child not show rotator movements of the jaw while chewing solid food?
23. When drinking liquids, does the child / your child not drink water in 4-5 consecutive swallows?
24. When drinking liquids or eating solid food does the child / your child not maintain adequate lip seal?
25. During drinking or eating solids, are the up-down tongue movements performed inadequately?
26. Does the child / your child not open his/her mouth when food is presented on a spoon?
27. Does the child / your child not drink from a cup placed near the lips and held by an adult?
28. Does the child / your child show any signs of stress before, during, or after feeding?
29. During the process of feeding, are the oral protective reflexes abnormal with respect to:
    - Rooting
    - Sucking
    - Coughing
    - Gagging
30. Does the child / your child show hyper or hyposensitivity or aversive responses to oral input?
31. Does the child / your child assume inadequate / bad posture while feeding?
32. Does the child / your child show noisy breathing during or after feeding sessions?
33. Does the child / your child tire easily during feeding (even before consuming adequate intake)?
34. Does the child /your child show discomfort if the following are present during the feeding period:
    - Bright lights,
    - Noisy surroundings
    - Running TV
    - Movements of siblings or others
35. While feeding the child / your child, are the following behaviors observed:
    - *Tongue-tip elevation*: the tip of the tongue is held firmly against the hard palate behind the upper alveolar ridge potentially interfering with nipple insertion (if breast or bottle fed) or with insertion of spoon or fed with fingers (if fed orally).
    - *Tongue retraction:* The tongue sits back in the mouth, well behind the alveolar ridges causing poor contact between the tongue and the nipple (if breast or bottle fed) or spoon or fed with fingers (if fed orally), to stimulate appropriate tongue movements. Strong neck hyperextension can also contribute to tongue retraction by pulling the tongue back into the mouth.
    - *Tongue protrusion:* The tongue pushes outward instead of moving in the normal wavelike anterior-posterior pattern. The tongue may compress the nipple, with

little suction generated, leading to inefficient sucking. This pattern may be seen in children who have sucked on endotracheal tubes and those with low tone.

- *Excessive Jaw Excursion*: The jaw moves in a greater range than expected and the movement is poorly graded. Tongue contact on the nipple may be poor, diminishing both compression and suction. Lip seal can also be compromised, further impairing sucking.

36. Does the child / your child not continue smoothly into inspiration/expiration cycle after the swallow effort?
37. Does the child / your child attempt to breathe through mouth or through the nose during swallow phase?
38. Does the child / your child not exhale smoothly post swallow and comfortably holds breath during swallow for a minimum period of 5 seconds?
39. Does the child / your child show the following:
    - Clear the throat frequently after every swallow by coughing
    - Take sips of water after every bolus intake
    - Requires the food to be modified to thin liquids to facilitate swallow
    - Requires more time between two spoons of food
    - Requires more time to swallow one bolus
    - Hoarse/wet/gurgly voice quality after every swallow
    - Post nasal drainage during the feeding session
    - Excessive phlegm in the throat during the feeding session
    - Requires 100% supervision or assistance during each bolus intake of the feeding process
    - Sneezes frequently after feeding
40. Does the child / your child chew or swallow ineffectively due to lack of awareness of food in the mouth?
41. Is the child / your child unaware of pooled saliva and drooling
42. Is the child / your child unaware of food stuck in the teeth or on side of lips/face?
43. Does the child / your child spit up or vomit frequently while feeding?
44. Do you not see laryngeal elevation during swallow in the child / your child?
45. Does the child / your child experience a burning sensation in the mouth/throat/chest post swallow?
46. Do you observe burping/ belching or frequent hiccups in the child / your child?
47. Does the child / your child regurgitate after lying down or gag towards the end/after meals?
48. Does the child / your child complain of a feeling of a lump/congestion in the chest or pain/pressure/discomfort in the chest after eating or drinking?
49. Does the child / your child pocket food in the mouth while eating?
50. Does the child / your child pocket food in anterior or lateral sulcus after swallow?

Appendix B

QUESTIONNAIRE TO ASSESS AWARENESS OF DIAGNOSTIC ISSUES & REHABILITATION OF CHILDREN WITH FAILURE TO THRIVE (FTT)

(*Note:* The caretakers or the Clinician can fill up the details in this part of the questionnaire. In illiterate group of clients, this part of the information will be entered by the clinician after reviewing the medical reports of the clients if available)

Sr. No.	*Items*	*Yes*	*No*
1.	Are you aware of the term "***Failure to Thrive***" (FTT)? **If the answer to question No 1 is 'YES', please proceed to the following questions from No 2.** **If the answer to question No 1 is "NO", then you may stop here without proceeding to answer any of the questions from No. 2**		
2.	Do you know that the incidence of malnutrition in FTT individuals is high?		
3.	Do you know that as a result of not receiving adequate nutrition, your child can suffer from growth retardation?		
4.	Do you know that medication can also reduce the stiffness of the muscles and help them relax?		
5.	Do you know that a physiotherapist can help with contractures? (As the muscles are stiff and not much movement is made, the muscles do not stretch and sometimes stop growing. They become fixed in an abnormal position)		
6.	Do you know that surgery will be required if your child is not able to rest the heel		

and walks on his/ her toes

7. Do you know that a suitable orthotic device (like braces) can stretch and exercise the muscles and enable it to grow?
8. Have you consulted a specialist doctor for all the gastrointestinal/ cardiac pulmonary endocrine/ renal disorders?
9. Are you aware of any special feeding and assistive devices to help you and your child?
10. Do you use such feeding devices?
11. Have you consulted an Occupational therapist for any of your child's problems?
12. Is your child meeting the daily nutritional requirement standards?
13. Does your child consume from all the 5 major food groups? (Carbohydrates, meat, fruits, vegetables, dairy, fats and oils)
14. Do you feed your child often?
15. Is your child taking any supplementary nutrition in the form of tablets? (multi-vitamins etc)
16. Is your child getting enough exercise?
17. Is your child attending any speech/physio/occupational therapy?
18. Do you seek the advice of medical professional for your child periodically?
19. Is your child's weight becoming normal/ is already normalized according to his/her age and gender requirements?
20. Are you aware that your child's nutritional needs are different from others children and that your child requires special treatment?
21. Is there a high-risk environment in which FTT often occurs? (e.g., poverty, high family stress, and poor parental coping skills)
22. Is your child's juice consumption limited to 8 –16 oz per day?