

**ASSESSMENT OF NUTRITIONAL STATUS, MEALTIME
BEHAVIOUR AND DIETARY INTAKE IN CHILDREN AND
ADOLESCENTS WITH AUTISM**

by

Niharika Chitrakar

Department Of Nutrition and Dietetics

Central Campus of Technology

Institute Of Science and Technology

Tribhuvan University, Nepal

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**Assessment of Nutritional Status, Mealtime Behaviour and Dietary
Intake in Children and Adolescents with Autism**

*A dissertation submitted to the Department of Nutrition and Dietetics, Central Campus of
Technology, Tribhuvan University, in partial fulfilment of the requirements for the degree of
B.Sc. Nutrition & Dietetics.*

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Niharika Chitrakar

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Institute of Science and Technology

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Tribhuvan University
Institute of Science and Technology
Department of Nutrition and Dietetics
Central Campus of Technology, Dharan

Approval Letter

This *dissertation* entitled *Assessment of Nutritional Status, Mealtime Behaviour and Dietary Intake of Children and Adolescents with Autism* presented by **Niharika Chitrakar** has been accepted as the partial fulfillment of the requirements for the **B.Sc. degree in Nutrition and Dietetics**.

Dissertation Committee

1. Head of Department
(Mr. Kabindra Bhattarai, Asst. Prof)

2. External Examiner
(Mr. Ananta Raj Poudel)

3. Supervisor
(Mr Aashik Kumar Jha, Teaching Assistant)

4. Internal Examiner
(Mrs. Pallavi Vyas Jaisaini, Teaching Assistant)

July, 2023

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Abstract

The objective of the study was to assess the nutritional status of autistic children and adolescents at various Autism centres in Kathmandu valley, Nepal. A cross-sectional descriptive study was carried out on 104 autistic children and adolescents aged two to fifteen years old. Data were collected by using a pretested, semi-structured questionnaire to obtain information on socio-economic and demographic characteristics, child characteristics, child-caring practices, health and immunization practices, maternal characteristics, mealtime behaviour, gastrointestinal disorders and nutrient intake. Anthropometric measurements (height, weight, MUAC) were used to determine if the children were underweight, stunted, thin, overweight or obese based on WHO reference. Collected data were analyzed using SPSS version 20 and WHO Anthro 3.2.2 version. The Chi-square test and the Fischer exact test were used to test the significant association between various factors of malnutrition.

The study revealed that overall 4.8% and 9.6% of participants with autism were moderately underweight and moderately stunted respectively. Moreover, 5.8% of autistic children were found to be moderately thin, 14.4% were found to be overweight, 5.8% were obese and 1.9% were severely obese. Significant associations between underweight and the mother's education level, birth weight, age at first pregnancy, the child's turning his/her face or body away from food, the consumption of processed foods, energy intake, and fat intake were found. Findings showed that age at first pregnancy, exclusive breastfeeding, processed food, calorie and fat intake, and consumption of processed food were all substantially connected with stunting. The child's age, child closing his/her mouth tightly when food is presented, acceptance of or like a variety of meals, consumption of processed foods, and calorie intake were all strongly associated with thinness/obesity in children.

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List of Abbreviations

Abbreviations	Full forms
ASD	Autism spectrum disorder
ATEC	Autism Treatment Evaluation Checklist
BAMBI	Brief Autism Mealtime Behavior Inventory
BAZ	BMI for Age z-score
CARS	Childhood Autism Rating Scale
CDD	Childhood Disintegrative Disorder
DSMV	Diagnostic and Statistical Manual of Mental Disorders
FFQ	Food Frequency Questionnaire
FGID	Functional Gastrointestinal Disorder
GI	Gastrointestinal
GFCF	Gluten-free casein free
HAZ	Height for Age z-score
NIN	National Institution of Nutrition
PDD-NOS	Pervasive Developmental Disorder not otherwise specified
QPGS	Questionnaire on Pediatric Gastrointestinal Symptoms
QPGS-RIII	Questionnaire on Pediatric Gastrointestinal Symptoms Rome III Version
RDA	Recommended Dietary Allowance
SPSS	Statistical Package for the Social Sciences
TD	Typically developing

WAZ	Weight for Age z-score
WHO	World Health Organization

Part I

Introduction

1.1 Background to the study

Autism spectrum disorder (ASD), also known as autism, refers to a group of pervasive neurodevelopmental disorders that involve moderately to severely disrupted functioning regarding social skills and socialization, expressive and receptive communication, and repetitive or stereotyped behaviours and interest (D. S. Mandell *et al.*, 2002). They include autistic disorder, Rett syndrome, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger syndrome (Pugh, 2009). The disorder is characterized by core characteristics in two areas: social communication and limited, repetitive sensory-motor behaviours (Lord *et al.*, 2018).

Epidemiological data estimate the global prevalence of ASDs to be one person in 160, accounting for more than 7.6 million disability-adjusted life years and 0.3% of the global burden of disease (WHO, 2013). The overall prevalence of ASD is 0.36% in Asia, with the prevalence higher in East Asia (0.51%) than that in West Asia (0.35%) and South Asia (0.31%) (Qiu *et al.*, 2020). The reported prevalence of ASD in South Asia ranged from 0.09% in India to 1.07% in Sri Lanka. An alarmingly high prevalence (3%) was reported in Dhaka city (Hossain *et al.*, 2017). In terms of sex, ASD prevalence is more biased in males as compared with females in several types of research with a ratio of 4.5:1 as reported by Christensen *et al.* (2018) and 4.2:1 as reported by Fombonne (2009).

Autism is rarely diagnosed in Nepal as there is a lack of awareness of autism by parents and professionals (Heys *et al.*, 2017). This delay in diagnosis can delay proper intervention which can also lead to a lack of knowledge on nutrition resulting in poor health among autistic children. To date, there have been only a handful of studies on the nutritional status of these children in Nepal. On April 2nd 2008, Autism Care Nepal was founded by a group of parents of children with autism to provide support to families with children on the autism spectrum. Besides direct care, the organization also focuses on awareness programs through various media campaigns including education for teachers, doctors, psychologists, and students.

According to Qiu *et al.* (2020), ASD prevalence is increasing in Asia, however, a study of 4098 rural Nepali children (9–13 years) reported an estimated prevalence of 0.3 (Heys *et*

al., 2017) which is lower than the reported global prevalence of 1–2% (Elsabbagh *et al.*, 2012; Lord *et al.*, 2018). This discrepancy indicates a potential under-detection and under-diagnosis of autism, as well as the delays in diagnosis reflecting a likely lack of knowledge of autism among professionals and caregivers (R. Shrestha *et al.*, 2021). Similarly, an occurrence of feeding problems among autistic children (Marí-Bauset *et al.*, 2015) along with the absence of nutritional knowledge among the parents (Heys *et al.*, 2017) has resulted in micronutrient deficiency and deviation from normal anthropometric measurements as compared to typically developing children.

The study was carried out to assess the nutritional health of autistic participants and to shed light on the occurrence of gastrointestinal diseases and mealtime behaviour in the participants. The results of this study can help in nutritional counselling of the children and encourage the parents to take necessary steps in improving their children's nutritional status.

1.2 Problems statement and justification

Nutrients and growth factors regulate brain development during fetal and early postnatal life. Beginning with the stage in utero, dietary consumption has an impact on cognitive processes, mood, and brain functioning in all age groups. As a result, nutritional deficiencies can cause a wide range of age-dependent clinical symptoms that have an impact on how well the central nervous system functions (Georgieff, 2007).

Children with Autism Spectrum Disorder often demonstrate selective eating behaviour and food patterns which can be separated into three categories: food selectivity based on type and texture, food refusal, and disruptive mealtime behaviours (DeMand *et al.*, 2015). Among these problems, food selectivity is often one of the most common causes (Ledford and Gast, 2006). Clinical trials have documented the frequency of problematic eating behaviours as high as 72% to 77% of children with ASD. These behaviors may inhibit the quality of nutrient intakes, and thus compromise nutritional status and optimal growth in children with autism (Altenburger, 2010).

Children with ASD consume less than the recommended amounts of certain nutrients from food which can lead to insufficiency in vitamins and minerals in their bodies (Hyman *et al.*, 2012). Similarly, malnutrition was found to occur in children with ASD with underweight being the most common followed by stunting and then wasting (Y. M. Al-Farsi *et al.*, 2011b). In contrast, the differences in eating patterns and behaviour have led to

discrepancies in the findings of various research with very mixed results concerning height, weight and BMI in children with ASD (Ho *et al.*, 1997; Hediger *et al.*, 2008; Y. M. Al-Farsi *et al.*, 2011b; Zimmer *et al.*, 2012).

Out of many medical complications related to ASD, gastrointestinal problems have gained a lot of interest due to their reported incidence and correlation with symptom intensity (Hsiao, 2014). Autistic children are likely to suffer from various gastrointestinal problems including constipation, diarrhoea, stomach bloating, gastro esophageal reflux, bloody stools, vomiting and gaseousness (Susan E Levy *et al.*, 2007b; Coury *et al.*, 2012; Hsiao, 2014).

Autism is rarely diagnosed in Nepal, few clinicians know anything about it, and there is insufficient data in academia (M. Shrestha and Santangelo, 2014). There is also a striking lack of awareness of autism by parents and professionals (Heys *et al.*, 2017) which can contribute to delayed identification and diagnosis of autistic children (Planche *et al.*, 2004; M. Shrestha and Santangelo, 2014). The delay in diagnosis of mental disorders especially ASD can delay proper intervention with the parents likely to adopt outdated beliefs on autism which can further jeopardize the prognosis process (Heidgerken *et al.*, 2005). Furthermore, this will lead to a lack of knowledge on nutrition resulting in poor health and increased morbidity in society (Yaseen *et al.*, 2020).

The study aimed to assess the nutritional status, mealtime behaviour and the occurrence of various gastrointestinal problems in ASD children in Kathmandu Valley. To date, there have been only a handful of studies on the nutritional status of these children in Nepal.

1.3 Objectives of the study

1.3.1 General objective

To assess the nutritional status of autistic children in Kathmandu valley.

1.3.2 Specific objective

1. To assess the anthropometry of children and adolescents with autism using various anthropometric measurements.
2. To assess the nutrient intake in children and adolescents with autism.
3. To assess mealtime behaviour in children and adolescents with autism.
4. To study the occurrence of gastrointestinal problems among autistic children and adolescents.

1.4 Significance of the study

1. The purpose of the study is to assess the nutritional health of children with ASD and to investigate whether it is under previous research work.
2. This investigation will help to shed light on the occurrence of mealtime behaviour and the importance of nutrition among children suffering from mental disorders such as ASD.
3. The study will also help to assess the dietary pattern of these children in developing countries such as Nepal to get a better insight on the discrepancies in intake of nutrients which will further help in nutritional counselling of the children and encourage the parents to take necessary steps in improving their children's nutritional status.

Part II

Literature review

2.1 Autism Spectrum Disorder

Autism spectrum disorder is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviours used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition to the social communication deficits, the diagnosis of autism spectrum disorder requires the presence of restricted, repetitive patterns of behaviour, interests, or activities (APA, 1980).

In 1910, Paul Eugen Bleuler, a Swiss psychiatrist, used the word 'autism' for the first time when describing specific symptoms of schizophrenic patients (Greydanus and Toledo-Pereyra, 2012; Cook and Willmerdinger, 2015). Kanner (1943), an American psychiatrist was the first to publish a paper on autism named "Autistic disturbances of affect contact" where he used the term "early infantile autism" to describe children who lacked interest in other people (Faras *et al.*, 2010). Similarly, Hans Asperger, an Austrian paediatrician, was the first to independently describe another set of kids in 1944 who exhibited comparable tendencies but to a lesser extent and with greater intellectual capacity. Since then, Asperger syndrome, a more severe form of autism, has been given his name. (Klin, 2003; Faras *et al.*, 2010). It was not until the 1980s that the term pervasive developmental disorders was first used (APA, 1980; Faras *et al.*, 2010).

Different variants of the disorder have been identified which are brought under the broad umbrella of autism spectrum disorders (ASD). Autistic disorders, Asperger's disorder, childhood disintegrative disorder and Pervasive Developmental Disorder not otherwise specified (PDD-NOS) which were considered as different disorders previously have all been under the preview of Autism Spectrum Disorder, as per DSMV (Vijayalakshmi *et al.*, 2017).

According to the Diagnostic and Statistical Manual of Mental Disorders published by the American Psychiatric Association, there are five main sub-types of autism.

- a. Autistic Disorder (Autism, childhood autism, early infantile autism) - symptoms at a more intense level. (Vijayalakshmi *et al.*, 2017)
- b. Asperger Syndrome (Asperger's disorder or simply Asperger's) – milder level, very intelligent, much harder time socially, and have problem with communicating,

repetitive motions, under developed motor skills, low functioning (Vijayalakshmi *et al.*, 2017)

- c. Childhood Disintegrative Disorder (CDD, dementia infantile, disintegrative psychosis or Heller's syndrome)-rarest and most severe, children develop normally and then quickly lose many social, language, and mental skills, usually between ages 2 and 4, ability to interact with other children and will lose interest in play, a problem with the motor skills (Vijayalakshmi *et al.*, 2017).
- d. Pervasive Developmental Disorder (PDD-NOS or atypical autism) – it is more severe than Asperger's syndrome, but not as severe as autistic disorder. They need the same interventions and help that autistic children require and the differences between PDD-NOS and autism are minor (Vijayalakshmi *et al.*, 2017).
- e. Rett's Syndrome is rare and relatively little-known type of autism and it only happens with girls. The problems with muscle atrophy, and tend to do repetitive hand motions. Almost they are always mentally retarded to some degree. These girls are very low functioning and will need care for most of their lives (Vijayalakshmi *et al.*, 2017).

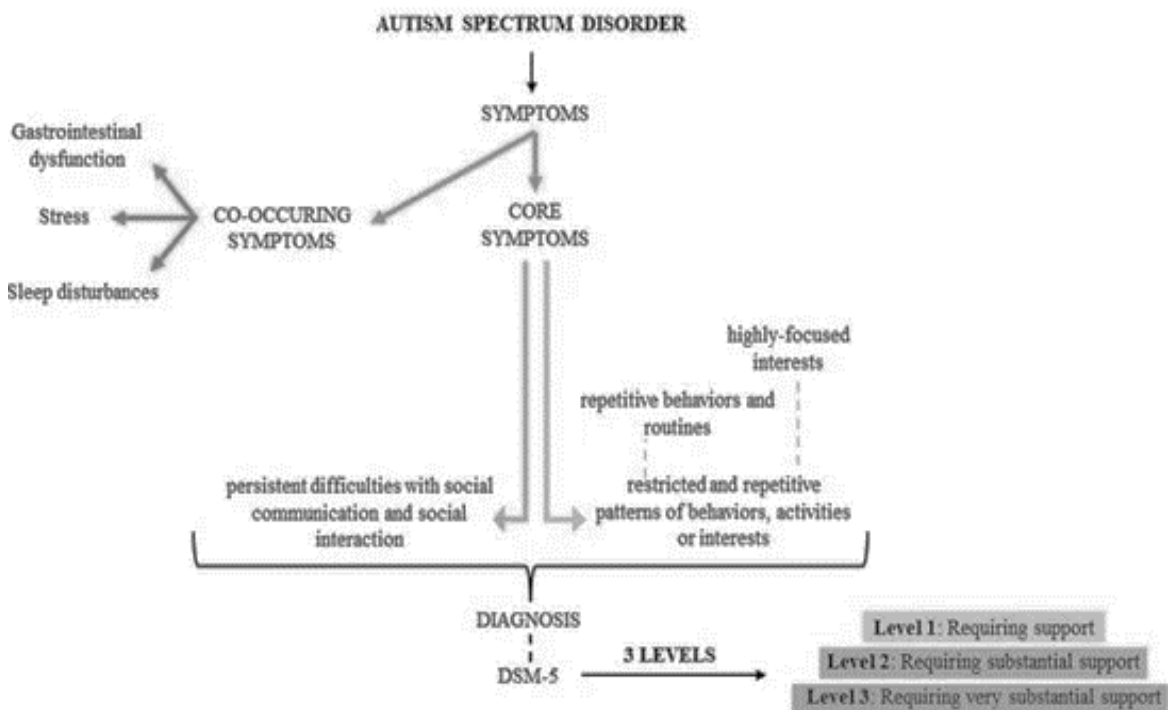


Figure 2.1: Characteristics of autism spectrum disorder (ASD) (Robea et al., 2020)

2.2 Prevalence

The prevalence of typical autism across the world is generally reported to be 10 per 10,000.(Fombonne, 2003; Duchan and Patel, 2012). A study analyzing data over 11 years, from 1997 to 2008, reported the prevalence of autism in children aged 3 to 17 years to be 47 per 10,000(Boyle *et al.*, 2011; Duchan and Patel, 2012). In Asia, the overall prevalence of ASD was found to be 0.36% (95 % CI: 0.16–0.79 %) (Qiu *et al.*, 2020). A study of 4098 rural Nepali children (9–13 years) reported an estimated prevalence of 0.3 ASD (Heys *et al.*, 2018; R. Shrestha *et al.*, 2021).

Autism spectrum disorder is diagnosed four times more often in males than in females (APA, 1980). Similar biases of autism in males have also been found in several other types of research (Baird *et al.*, 2006; Christensen *et al.*, 2018) whereas few studies have suggested that there are subtle yet potentially important differences between the male and female ASD phenotype (Hartley and Sikora, 2009).

2.3 Etiology

The exact cause of autism and the other ASDs is still not known. The etiologic theories have changed over the years (Faras *et al.*, 2010). A substantial body of literature strongly suggests a genetic foundation for autism. (Caglayan, 2010; El-Fishawy, 2010; Geschwind, 2011).

Various environmental factors have also been suggested as the possible cause of autism. Epidemiological studies have indicated that prenatal infections such as rubella and cytomegalovirus account for a few cases of autism (Muhle *et al.*, 2004). Similarly, the role of heavy metals in the etiology of autism is controversial and requires more research (Muhle *et al.*, 2004; Faras *et al.*, 2010). There have been growing public concerns that vaccination was one of the causes of autism especially the MMR vaccine as hypothesized by Sabra *et al.* (1998). However, Miller (2003) stated that there is no epidemiologic evidence suggesting an association between MMR vaccination and autism. Most autistic children complain of gastrointestinal problems due to which human gut bacteria has been hypothesized to contribute to the etiology of autism by Louis (2012), however, this requires further investigation.

2.4 Onset

The onset of autism is believed to occur in one of two patterns: congenital and regressive. Congenital autism, as the term suggests, is when autistic symptoms first occur at birth or

soon after; children who are said to be developing autism in this way frequently exhibit developmental delays and unusual behaviours from the start. Regressive, on the other hand, describes the emergence of autistic symptoms after a period of typical development. These kids are typically described as developing normally until a certain age, at which point they start to lose previously learned skills and stop moving forward at their previous rate (Goin-Kochel and Myers, 2005). In congenital autism, most parents recognized delayed speech and language development as the initial symptom followed by abnormal socio-emotional response, and medical problems or delay in milestones (De Giacomo and Fombonne, 1998).

2.6 Nutritional status of autistic children

There have been several studies on the nutritional status of children with autism, however, the results are inconsistent and sometimes even contradictory. A few researches have suggested that autistic children are at risk of being overweight or obese (Xia *et al.*, 2010; Souza *et al.*, 2012). Similarly in a study among autistic boys, Hediger *et al.* (2008) found that boys with autism were significantly heavier and had a higher BMI than average. Hyman *et al.* (2012) found evidence of differences in patterns by age: children with ASD ages 2-5 years are more likely to be overweight and obese. In contrast observed (Sadowska and Cierebiej, 2011) that 30% of ASD children have low body weight and another study (Bauset *et al.*, 2013) reported ASD children were found to have a lower BMI than controls.

Similarly, undernutrition has also been reported by several researches. Among 100 autistic children aged 3-5, M. Al-Farsi *et al.* (2011a) found 3.9% of children to be underweight, followed by 3.1% of children who were wasted and 2.3% who were stunted. The overall prevalence of malnutrition was significantly higher among boys than girls (12.4 vs. 8.4). In a recent study by (Eow *et al.*, 2021), the prevalence rates of underweight, stunting, wasting/thinness and overweight/obesity were 9.3%, 8.0%, 4.0%, and 21.5%, respectively.

2.7 Mealtime Behaviour and dietary patterns of autistic children

According to certain evidence gathered from assessment questionnaires, ASD children experience more feeding issues than other pediatric demographics (Aponte and Romanczyk, 2016). Feeding problems commonly fall into one of three categories; food selectivity, food refusal and disruptive mealtime behaviours (Schreck *et al.*, 2004a; K. A. Schreck and Williams, 2006; Bandini *et al.*, 2010). Food selectivity, or only consuming a limited variety

of meals by kind, texture, or presentation, is the most common feeding concern among children with ASD, according to research (Ahearn *et al.*, 2001; Lukens and Linscheid, 2008). Children with ASD are found to have higher levels of consumption of foods high in energy than typically developing children (Evans *et al.*, 2012). Similarly, they were found to eat fewer vegetables when compared with typically developing children. By contrast, the fruit was found to be consumed in adequate amounts by both groups, probably because of its texture and sweet taste (Diolordi *et al.*, 2014). The results from the analysis of the numbers of specific foods eaten within each food group, carried out by Kimberly A Schreck *et al.* (2004b) supported that children with autism eat fewer foods within each food group than typically developing children. Another study conducted in India by Malhi *et al.* (2017) also found that food group intake among ASD children was less as compared to typically developing children.

2.8 Nutrient intake of autistic children

The selective eating pattern and preferences for energy-dense of autistic children have resulted in varying results in calorie intake. One study reports that children with autism were not significantly different in their intake of total calories, carbohydrates, protein, or fats (Johnson *et al.*, 2008). However, Ho *et al.* (1997) reported that the group consumed more carbohydrates and less fat than the average Canadian child but had a similar calorie intake. Similarly, Seema Siddiqi *et al.* (2019b) reported that among the age 2–4 years majority of them had adequate calorie intake but in case of other age groups; i.e., 5–7 years, 8–10 years and 11–13 years, adequacy of calorie intake was lesser.

The feeding problem and food selectivity associated with ASD have given rise to nutritional vulnerability among autistic children. Due to this, they are more likely to have restricted intakes, which can lead to deficiencies in essential minerals or vitamins. In a study conducted in India by Seema Siddiqi *et al.* (2019b), the vitamin and mineral consumption of study participants was highly variable, with the inadequacy of vital micronutrients. Intake of two water-soluble vitamins, B1 (thiamine) and B2 (riboflavin) and calcium, iron, and zinc intakes were insufficient among a majority of the subjects (S. Siddiqi *et al.*, 2019a).

2.9 Gastrointestinal problems in autistic children

GI symptoms among autistic children were first reported by Goodwin *et al.* (1971). Parents of children with autism spectrum disorders typically report GI discomfort and

irregularities in stool consistency (Susan E Levy *et al.*, 2007b). In comparison to children with usual development (28%) and children with developmental delays (42%), children with ASD (70%) were more likely to have gastrointestinal problems, according to a research of 150 children (50 ASD, 50 controls, and 50 children with other development delays (Valicenti-McDermott *et al.*, 2006). From then on several researches have reported the occurrence of different gastrointestinal problems in autistic children including chronic diarrhea, excessive gas, abdominal discomfort, abdominal distension (Horvath *et al.*, 1999), and constipation (Quigley and Hurley, 2000). Among these problems, constipation affect children with ASD far more often than children with TD. Those with ASD were at least three times as likely to have more frequent GI symptoms than children with TD (Chaidez *et al.*, 2014).

Although the exact etiology of these gastrointestinal issues is unknown, a child can consume a relatively self-restricting diet that could lower the diversity of foods and nutrients required to sustain healthy gut function if they have noticeable food dislikes or selectivity for various reasons, such as flavour, texture, or temperature.(Chaidez *et al.*, 2014). However, a study conducted by Gorrindo *et al.* (2012) found no association between dietary intake and GID in autistic children.

Similarly, some environmental and genetic risk factors for autism show strong correlations with digestive problems (Hsiao, 2014). The results of a study by Campbell *et al.* (2009) suggest that the chance of developing autism spectrum disease, which includes family gastrointestinal disorders, may be raised as a result of disturbed MET signalling. changing food habits, decreased gut permeability, and increased biodiversity of the gut microbiome are additional potential pathophysiological processes that connect ASD with gastrointestinal disorders as reported by Geir *et al.* (2020).

Adams *et al.* (2011) strongly suggest that gastrointestinal problems are associated with autism severity. The autism group with low GI problems had much lower scores on the ATEC and each of its four subscales compared to the autism group with high GI problems. In contrast (Mazefsky *et al.*, 2014) have reported that the level of ASD symptoms, adaptive behaviour, or any of the externalizing problem measures did not substantially differ between children with and without GI issues. Hence the association between GI problems and the severity of ASD symptoms needs to be further investigated due to these contrasting results.

2.10 Relationship between nutrition and autism.

The interest among scientists in examining the connection between nutrition and ASD has grown during the past few years. The etiology of ASD may be greatly influenced by nutrition, according to emerging data. Specific maternal nutritional deficits also seem to be linked to an elevated risk in offspring (Onaolapo and Onaolapo, 2018). Nutrients whose deficiencies during pregnancy has shown to increase the risk of ASD include Vitamin D (M. Wang *et al.*, 2017), folic acid (H., 2013; Surén *et al.*, 2013) and iron (Schmidt *et al.*, 2014). After birth, nutritional deficits are frequently observed in autistic children. Children with ASD have been observed to have restricted diets and inadequate nutrient intake, which has led to a considerable decrease in the consumption of macronutrients compared to children without ASD, with iron deficiency and vitamin A deficiency having the highest rates of occurrence (Xiao Liu *et al.*, 2016b). In children with ASD, such micronutrient insufficiency may also be related to how severe the behavioural symptoms are (Onaolapo and Onaolapo, 2018).

Nutritional management of ASD comprises either adding nutrients that are often known to be deficient in children with ASD or taking away foods or food items from the diet that are thought to cause allergies and food intolerances (such as casein and gluten) and contribute to the symptoms of ASD (Onaolapo and Onaolapo, 2018).

Kidd (2002) states that vitamins A B3, C, and folic acid; the minerals calcium and zinc; cod liver oil, all offer benefits in the management of ASD. There have also been various subtractive dietary techniques applied. The use of gluten-free casein-free (GFCF) diet has gained popularity with one study (Whiteley *et al.*, 2010) reporting that at 8, 12, and 24 months after the start of the intervention, the introduction of a gluten- and casein-free diet had a substantial positive group effect on the core autistic and associated behaviours of prepubescent children diagnosed with ASD as well as abnormal urine findings. The GFCF diet is based on the "opioid excess theory," which postulates that some ASD sufferers have increased gut permeability and insufficient synthesis of the enzymes needed to digest meals containing gluten and casein. A significant amount of the peptides generated from casein and gluten are only partially converted to amino acids. The blood-brain barrier is breached by the peptides as a result of increased gut permeability, allowing them to enter the bloodstream and travel to the brain. Their interaction with opioid receptors causes ASD symptoms. (Mulloy *et al.*, 2010; Onaolapo and Onaolapo, 2018). Similarly, ketogenic diets

have also been used in the management of ASD with El-Rashidy *et al.* (2017) reporting both the ketogenic and GFCF diet groups significantly improved their Autism Treatment Evaluation Checklist (ATEC) and Childhood Autism Rating Scale (CARS) scores when compared to the control group, while the ketogenic diet group outperformed the GFCF diet group in terms of cognition and sociability.

The dietary approach to managing ASD is growing in acceptance, but research on its efficacy is still in its early stages and only partially available (Onaolapo and Onaolapo, 2018)

2.11 Autism in Nepal

Sufficient data is not available from Nepal to provide Nepal-specific prevalence. Also, autism is rarely mentioned in academia in Nepal (M. Shrestha and Shrestha, 2014). The Autism Care Nepal Society website states that there is “no reliable estimate for the prevalence of autism in Nepal, as autism is not known to many people”. The only prevalence study in Nepal was carried out by Heys *et al.* (2018) in which 4098 rural Nepali children (9–13 years) reported an estimated prevalence of 0.3 ASD.

Heys *et al.* (2017) have reported that lack of knowledge of autism as a named concept, notably among parents of non-autistic children, primary school teachers, community health professionals, early child development instructors, and traditional healers, which was thought to be especially true in rural places. Heys *et al.* (2017) also reported that people in Nepal have a misconception about ASD and mistake autistic children’s behaviour as being “stubborn” or “naughty”, with some parents even stating that ‘community people don’t understand exactly about autism, they don’t know about it, so they think negatively about autistic children, saying our child is crazy’ [pagaal/baula/sanki] (parent of an autistic child). M. Shrestha and Shrestha (2014) stated that children are taken to temples and faith healers before being taken to a proper physician due to traditional beliefs. Similarly, most of the Pediatricians in Nepal have inadequate knowledge and practice related to Autism Spectrum Disorder. In a survey conducted by Khatri *et al.* (2011), results showed that 64.8 percent of Pediatricians have inadequate knowledge of Autism Spectrum Disorder and that 13% believed that Autism is a form of psychosis. It is notable and alarming that respondents who had no prior knowledge of the illness lacked information and awareness (Heys *et al.*, 2017). Caregivers’ knowledge and help-seeking behaviours influence early identification and diagnosis of developmental disability (R. Shrestha *et al.*, 2021), However insufficient knowledge and misconceptions about ASD among parents will have negative impacts on

early identification and intervention of ASD (D. S Mandell and Novak, 2005; J. Wang *et al.*, 2012). This has been seen to be true in the case of Nepal as parents noticed that something was wrong and sought medical help for their children at only around 28 months whereas the children were only diagnosed at around 56 months of age (M. Shrestha and Shrestha, 2014) with a recent study showing mean age of an ASD diagnosis in Nepal indicated it to be 58 months (R. Shrestha *et al.*, 2019). There is a need to close the gap between the age at which ASD can be identified and the average age at which it is currently diagnosed since the mean diagnostic age of ASD in Nepal is substantially older than the age at which an accurate diagnosis is attainable (R. Shrestha *et al.*, 2019).

Upadhyay and Ghimire (2019) carried out the first study in Nepal to examine food selectivity and mealtime behaviour problems in children with autism. The study describes the food selectivity, mealtime behaviour problem, nutrient intake and weight status in children and teens with Autism. Most of the children in the study were found to be overweight and were in the state of over-intake of total calories. Similarly, among 70 participants, 36 individuals (51.43%) were food selective while the remaining 34 (48.57%) were not food selective the study also determined that among 70 participants, 51.43% of autism children and teenagers do not have problematic mealtime behaviour while 48.57% of them have problematic mealtime behaviour (Upadhyay and Ghimire, 2019).

With the lack of co-operation from government bodies, the parents of autistic children together started Autism Care Nepal on April 2, 2008, to provide support to families with children on the autism spectrum. It is the only organization in the entire country which attempts to address the needs of children with autism. With help from international experts, the organization is building its resources and helping to raise awareness of autism in Nepal (M. Shrestha and Santangelo, 2014).

2.12 Assessment of nutritional status

The systematic process of gathering and analyzing data to make judgments regarding the kind and source of nutrition-related health concerns that impact an individual is known as nutritional assessment (BAPEN, 2022). The first phase in the nutrition and dietetic process is nutrition assessment, which is a systematic method of gathering and analyzing data to help determine the nature and root causes of nutrition-related health concerns that affect an individual, a group, or a population. It is a methodical approach to gathering, confirming, and analyzing data required to identify nutrition-related problems, the related etiologies, the

magnitude of the problem, as well as the symptoms and indicators displayed by the nutrition-related problem. The purpose of the nutrition assessment is to establish individual nutritional needs, document baseline nutritional parameters, identify nutritional risk factors and specific nutritional deficits, and identify medical, psychosocial, and socioeconomic factors that may affect the recommendation and administration of nutrition support therapy (Hickson and Smith, 2018). Two approaches are used to evaluate nutritional status: direct (which works with people and assesses the objective criteria) and indirect (which makes use of community health indicators that take dietary factors into account).

A. The direct method of nutritional survey

The direct method can be summarized as ABCD steps:

- a. Anthropometric method
- b. Biochemical and laboratory method
- c. Clinical examination
- d. Dietary evaluation method (Gibson, 2005b)

B. The indirect method of nutritional survey

The indirect methods of nutritional survey are:

- a. Ecological variables including agricultural crop production, food balance, health and educational services.
- b. Socio economic factors e.g. Family size, occupation, per capita income, population density, education, customs and social habits.
- c. Vital health statistics particularly infant (under 5) mortality and morbidity related to PEM, school-age child stunting and wasting, anaemia, goitre, diarrhoea, measles and parasitic infestation (Jelliffe and WHO, 1966)

2.12.1 Anthropometric method of nutritional assessment

Anthropometric measures evaluate body size and composition and are a reflection of illness, insufficient or excessive activity, and inadequate or excess dietary consumption (WHO, 1995). The measures vary with age, and occasionally with sex, race, and level of nutrition. They are especially helpful in situations where chronic protein and energy imbalances are

likely to have occurred. Anthropometric measurements have the additional benefit of providing information on past nutritional histories, which cannot be obtained with the same confidence using other assessment techniques. In some cases, they can detect moderate and severe degrees of malnutrition, but the methods cannot be used to identify specific nutrient deficiency states (Gibson, 2005b). Anthropometry is the most widely applicable, affordable, and noninvasive approach for determining the size, proportions, and composition of the human body (WHO, 1995).

2.12.2 Anthropometric indicators

Raw data by itself has no significance unless it is connected to another. As a result, raw measures from the various nutritional assessment methods are frequently combined to create "indices," such as height-for-age, BMI, etc. Indices are frequently assessed at the population level by comparison to established reference limits or cutoff points, for example, the percentage of persons who are underweight based on a BMI of less than 18.5 kg/m². When applied in this manner, the index and the reference limit or cut-off that it corresponds to are referred to as "indicators," a name that refers to its usage in nutritional evaluation (Gibson, 2005b). The most used anthropometric indicators are stunting (H/A), Wasting (W/H), underweight (W/A) and MUAC in under-five children and BMI in adults. These indicators help to get a clear sight of the nutritional status of the individual (INDEPTH, 2008).

2.12.3 Height for age (H/A)

Height-for-age (H/A) is a measure of linear cumulative growth. H/A deficits cannot evaluate short-term changes in malnutrition; instead, they suggest past or ongoing nutritional deficiencies and/or chronic or recurrent illnesses. "Shortness" is defined as low H/A in comparison to a kid of the same sex and age in the reference population. Extreme low H/A conditions known as "stunting" are when shortness is considered pathological. H/A is more commonly employed as a population indicator than for tracking individual growth (WHO, 2006).

The low height-for-age index indicates chronic malnutrition or historical under nutrition. It is unable to detect sudden changes in malnutrition. The phrase "length-for-age" refers to children under 2 years old; "height-for-age" refers to children over 2 years old. (Cogill, 2003).

Stunting is a sign of previously unsuccessful growth. It is linked to a variety of long-term problems, such as persistently low calorie and protein consumption, recurrent infections, persistently incorrect feeding practices, and poverty. The impacts of these long-term variables may not be reversed in children older than 2 years old. It is preferred to employ children under 2 years old for assessment purposes since their incidence of stunting is expected to be more susceptible to the effects of treatments than that of older children (Cogill, 2003).

Table 2.1: Classification of stunting according to height-for-age index (H/A), expressed as a Z-score (WHO, 2006)

Definition	Index
Normal/ Not stunted	> -2 z-score
Moderate stunting	-3 z-score \leq H/A < -2 z-score
Severe stunting	< -3 z-score

2.12.4 Weight for age

Weight-for-age (W/A) reflects the relationship between body mass and age. Interpretation is challenging since W/A is essentially a composite measure of height-for-age and weight-for-height. The phrase "lightness" refers to low W/A in comparison to a kid of the same sex and age in the reference population, but the term "underweight" is frequently used to refer to severe or pathological deficits in W/A. W/A is frequently used to track growth and gauge how the severity of malnutrition has changed over time (WHO, 2006).

Table 2.2: Classification of underweight according to weight-for-age index (W/A), expressed as a Z-score (WHO, 2006)

Definition	Index
Normal	> -2 z-score
Underweight	-3 z-score \leq H/A < -2 z-score
Severe underweight	< -3 z-score

2.12.5 Weight for height (W/H)

Weight-for-height (W/H) is a measurement that does not require age information that compares body weight to height. W/H is typically employed as a measure of current nutritional status and helps identify at-risk children and monitor short-term changes in nutritional status. W/H can also be utilized to provide markers of obesity on the other end of the spectrum. "Thinness" is defined as low W/H in comparison to a child of the same sex and age in a reference population. Extremely low W/H ratios are sometimes referred to as "wasting" (WHO, 2006).

Wasting is a sign of current or acute malnutrition brought on by real weight loss or inability to acquire weight. Inadequate food intake, improper feeding techniques, illness, infection, or, more commonly, a combination of these conditions are some of the causes. Wasting may alter quickly in both population groups and specific children, and it exhibits distinct seasonal patterns linked to variations in food supply or illness incidence, to which it is extremely sensitive (Cogill, 2003).

High weight-for-height is more commonly referred to as being overweight. Greater lean body mass can also contribute to high weight-for-height, even though there is a substantial association between high weight-for-height and obesity as determined by adiposity. Therefore, when referring to excess weight-for-height, fatness or obesity should not be used as a general term. However, because most people with high weight-for-height are obese, high weight-for-height can be used as a reliable indication of obesity on a population-wide basis (De Onis and Blossner, 1997).

Table 2.3: Classification of wasting according to weight-for-height index (W/H), expressed as a Z-score (WHO, 2006)

Definition	Index
Obesity	$\geq 3z$ -score
Overweight	+2.01 to +3 z-score
Normal	> -2 z-score
Moderately wasted	-3 z-score \leq H/A < -2 z-score
Severely wasted	< -3 z-score

2.12.6 Mid-upper arm circumference

The MUAC assesses both fat stores and muscle mass by measuring the diameter of the upper arm. Although it can be used to evaluate a pregnant woman's nutritional condition, it is predominantly utilized for children. The equipment needed for measurement is not complicated. Thus, the MUAC has been suggested as a substitute for other nutritional status indicators, particularly in cases when it is challenging to gather information on age, height, and weight (INDEPTH, 2008).

MUAC is a reliable indicator of the likelihood of immediate death and is reasonably simple to assess. It is used to quickly test for acute malnutrition in children aged 6 to 59 months (MUAC overestimates rates of malnutrition in the 6-12 month age group). Although it is not frequently used for assessment reasons, MUAC can be utilized for screening in emergencies. For determining the prevalence of under nutrition at the population level and evaluating acute adult under nutrition, MUAC is advised (Cogill, 2003).

Table 2.4: MUAC cut-off points for corresponding colour and interpretation (WHO, 2009)

Colour	Cut off points	Interpretation
Red	<115 mm	Severely acute malnutrition
Yellow	115 mm to <125 mm	Moderate acute malnutrition
Green	>125 mm	Well-nourished

2.12.7 BMI

Body mass index (BMI) is a measure used to define overweight and thinness. BMI is the ratio weight (in kg)/recumbent length or standing height (in m²). The BMI is largely employed in developing nations with age-independent cutoffs to detect adult chronic energy deficiency (or obesity). The index varies with age for children and teens, thus it must be read in relation to BMI-for-age reference charts even though there is some room for utilizing BMI for adolescents.

Table 2.5: Classification of BMI expressed as z-score (WHO, 2009)

Index	Definition
Severely thin	Below -3 SD
Moderately thin	-3 SD to -2 SD
Normal	-2 SD to 1 SD
Overweight	+1 SD to +2 SD
Obese	+2 SD to +3 SD
Severely obese	Above +3SD

2.13 Dietary method of nutritional assessment

Food and nutrient intakes can be estimated by quantitative and qualitative methods. A qualitative study gives information on the types of foods consumed, food preparation methods, food preferences, cultural influences, and attitudes toward foods whereas a quantitative survey provides data on the quantity of various foods consumed by individuals and/or populations. There is no one diet evaluation technique that is perfect. As a result, it is advised that, depending on the type and purpose of information needed, a combination of both techniques be employed (WHO, 2004). Dietary assessment can be done at different levels, from national to the individual level (Den Hartog *et al.*, 2006)

2.13.1 Individual dietary survey

This method is used to obtain information on the past and present food and nutrient intakes of an individual (Den Hartog *et al.*, 2006). Some of the methods are described below:

A. 24-hr recall

In a 24-hour recall, the subject is asked to estimate how much food and liquid they ingested over the preceding 24 hours. The 24-hour recall method's biggest benefit is its capacity to predict population-level nutrient intakes. This approach is frequently used to contrast dietary

recommendations with nutrient intakes. The primary drawback of recalls is that they are rarely an accurate representation of normal consumption (WHO, 2004).

It has been shown that the nutritional data produced by the 24-hr recall and the data from three-day diet records and other trustworthy dietary assessment methods are substantially connected. Additionally, it has been shown that the 24-Hour Recall Interview is less expensive to adopt than a three-day diet record (Posner *et al.*, 1992).

B. Food frequency questionnaire

The FFQ measures regular dietary intakes, making it the greatest approach currently available for investigations on the connection between food and illness. The core element of the food-frequency approach is that exposure periods should be longer than short ones, with the typical long-term diet (consumed over weeks, months, or years) being a more significant exposure time. The advantage of this approach is that it can offer more accurate data on typical intake than a few days' worth of diet records or recalls. However, the approach has a drawback in that it could not offer information on precise quantities or portion sizes (WHO, 2004).

2.14 Brief Autism Mealtime Behavior Inventory (BAMBI)

Brief Autism Mealtime Behavior Inventory is a standardized questionnaire used in clinical practice for an easy and adequate evaluation of feeding problems in children with ASD. The updated version is composed of 18 items and uses a Likert scale for reporting the frequency of behaviours (ranging from 1 = Never/Rarely to 5 = At Almost Every Meal) (Lukens and Linscheid, 2008). It is defined by 3-factors: (1) Limited variety, (2) Food refusal, and (3) Features of autism. The Limited Variety factor consists of 8 items that capture the child's willingness to try new foods and food categorized by preparation, texture, and type. The Food Refusal factor consists of five items that capture the problem behaviours observed when a child rejects a presented food (crying, spitting out food etc.). And finally, the Features of the Autism factor include items that reflect the behavioural characteristics of ASD, such as self-injurious behaviour, inattention, and repetitive behaviours during mealtimes (Lukens and Linscheid, 2008). The fact that the BAMBI was the first evaluation to address feeding issues frequently observed in the ASD population is a significant advantage of its development. Given that earlier assessments were not designed to address the specific

mealtime problem behaviour prevalent in this demographic, therefore this is very advantageous (Aponte and Romanczyk, 2016).

2.15 Rome III Diagnostic Questionnaire for the Pediatric Functional GI Disorders

The Questionnaire on Pediatric Gastrointestinal Symptoms—Rome III Version (QPGS-RIII)* is an adaptation and abbreviation of the Questionnaire on Pediatric Gastrointestinal Symptoms (QPGS) (Walker *et al.*, 2000) that was developed with the support of a grant from the Rome Foundation and that has undergone preliminary validation (Caplan *et al.*, 2005). The original QPGS assesses the Rome II symptom criteria for pediatric functional gastrointestinal disorders and additional gastrointestinal symptoms. The QPGS-RIII is an adaptation and abbreviation of the original QPGS. It was developed with input from the Rome III Child and Adolescent Committee and the Rome III Questionnaire Committee. Although the format and many items from the original QPGS have been retained, several new items have been included and the scoring has been revised to reflect changes in symptom criteria based on Rome III. Some items included in the original QPGS for research purposes have been deleted from the QPGS-RIII for brevity. The parent-report version of the QPGS-RIII is suitable for use by parents of children four years of age and older. The self-report version is suitable for administration to children ten years of age and older and is preferable to the parent report version when parents have limited knowledge of their children's symptoms. The questionnaire uses 5-point scales to measure the frequency, severity, and duration of symptoms. In addition, it may be scored to assess whether a patient meets the criteria for each of the individual functional gastrointestinal disorders. The questionnaire is followed by a coding system that identifies provisional diagnoses from the responses to the questions. The QPGS-RIII cannot substitute for the medical evaluation and clinical judgment required for an accurate diagnosis (Caplan *et al.*, 2005). (Gorrindo *et al.*, 2012) employed the Questionnaire on Pediatric Gastrointestinal Symptoms-Rome III Version (QPGS), a 71-item parent report tool that evaluates GI symptoms and categorizes functional GI illnesses following Rome III standards. Clinical examination was also included in his study. The researchers discovered that a clinical diagnosis of any gastrointestinal dysfunction was highly congruent (92.1%) with parent reports of any gastrointestinal dysfunction in people with ASD.

Part III

Materials and methods

3.1 Study area

The study was conducted in Autism Care Nepal, Avaani Foundation, and the Centre for Autism from November 20, 2021, to January 28, 2022. All of these organizations are located inside the Kathmandu Valley.

3.2 Study population

The population under study were children and adolescents 2-15 years of age who have been diagnosed to have ASD and who visit the autism centres for various forms of therapy.

3.3 Selection criteria

a. Inclusion criteria:

- Children who have been diagnosed to have ASD
- Children who are between the ages of 2-15

b. Exclusion criteria

- Children who are not diagnosed
- Children who are seriously ill might affect the child's intake or use of nutrients
- Children whose caretakers do not wish to take part in the survey

3.4 Research design

A cross-sectional study was conducted among the ASD children in each of the centres at the time of the field work. The field work consisted of the survey with the help of structured questionnaires followed by anthropometric measurements.

3.5 Sampling technique

The study was carried out by using a purposive sampling technique. The purposive sampling technique, also called judgment sampling, is the purposeful choice of a participant due to the qualities the participant possesses. It is a non-random approach in which the researcher determines what information is necessary and then searches for individuals who can and are prepared to supply it as a result of their training or experience (Bernard, 2017).

3.6 Sample size

104 children and adolescents who visited the different organisations for various forms of therapy, during the study period, were selected for the study using purposive sampling technique.

3.7 Research instruments

- a) Weighing machine: Weighing machine manufactured by Microlife Pvt. Ltd, with a capacity of 180kg and having the least count of 0.1 kg (1 piece) was used.
- b) Stadiometer: Stadiometer was used to measure height with a capacity of 197 cm and has the least count of 0.1cm.
- c) MUAC tape: For measuring mid-upper arm circumference (1 piece).
- d) A structured and pretested set of questionnaires.
- e) Measuring cups of 250 ml, 125 ml, 80 ml, 60 ml and 30 ml.

3.8 Study variables

Study variables were categorized into two groups: dependent variable and independent variable. The dependent variable of the study was the nutritional status of autistic children as indicated by stunting, wasting and underweight. Whereas, independent variables of the study were:

- A. Socio-economic and demographic variables: family type, ethnicity, father's occupation, father's education, mother's education, mother's occupation, head of household, family size, annual income, and food purchaser.
- B. Child characteristics: Age, sex, birth order, breastfeeding status, age gap with elder child, birth weight, and morbidity status.
- C. Child care practices: breastfeeding after birth, initiation time, colostrum feeding, breastfeeding frequency, exclusive breastfeeding, stop age, pre-lacteal feeds, complementary feeding practices, bottle feeding etc.
- D. Health and immunization practices: complete vaccination of child, intake of Vitamin A and deworming tablets, and health service-seeking practices.
- E. Maternal characteristics: age at marriage, age during first delivery, pregnancy-related factors: vaccinations, iron and folate intake, intake of extra food during pregnancy or lactation, knowledge about child malnutrition

- F. BAMBI questionnaire: information about the eating behaviour and nutritional intake of children with ASD
- G. Rome III Diagnostic Questionnaire for the Pediatric Functional GI Disorders: information about the various gastrointestinal problems among ASD children.

3.9 Data collection techniques

Data collection was spread over two phases, namely, initial contact with the school administrator and parents for completing the semi-structured questionnaire followed by anthropometric measurements of children. Informed consent was obtained before data collection.

The following techniques were used for data collection:

- A. A general questionnaire regarding the socio-demographic information, child description, child caring practices, health and immunization, and maternal characteristics was used
- B. Anthropometric measurements

The following anthropometric measurements were carried out thrice

- i. Weight: Weight was measured using a portable digital weighing scale. The instrument was placed on a firm, flat surface. Participants were requested to remove their footwear and socks, wear light clothes, stand on the scale with one foot on each side of the scale, face forward, place arms idly at their side and wait until asked to step off. Weight was recorded in kilograms (Cogill, 2003).
- ii. Height: Height was measured with a portable standardized stadiometer. For the height measurement, participants were asked to remove footwear and any hat or hair ties. They were requested to stand on the flat board facing the interviewer, heels against the backboard with their feet together and knees straight. They were asked to look straight ahead and not tilt their head up, making sure that their eyes are at the same level as their ears. Height was recorded in centimetres (Cogill, 2003).
- iii. MUAC: MUAC was measured using a standard MUAC tape. Any clothing that covered the child's left arm was asked to be removed. The midpoint of the arm was calculated by first locating the tip of the child's shoulder with fingertips then the child's elbow was bent to make a right angle and the midpoint was located. Then the arm was straightened and the MUAC take was wrapped around the arm at the located midpoint and the measurement was recorded in centimetres (Cogill, 2003).

- C. Brief Autism Mealtime Behavior Inventory is a standardized questionnaire used in clinical practice for an easy and adequate evaluation of feeding problems in children with ASD. The updated version is composed of 18 items and uses a Likert scale for reporting the frequency of behaviours (ranging from 1 = Never/Rarely to 5 = At Almost Every Meal) (Lukens and Linscheid, 2008). It is defined by 3-factors: (1) Limited variety, (2) Food refusal, and (3) Features of autism (Lukens and Linscheid, 2008).
- D. The Questionnaire on Pediatric Gastrointestinal Symptoms—Rome III Version (QPGS-RIII) is an adaptation and abbreviation of the original Questionnaire on Pediatric Gastrointestinal Symptoms (QPGS). It was developed with input from the Rome III Child and Adolescent Committee and the Rome III Questionnaire Committee. Although the format and many items from the original QPGS have been retained, several new items have been included and the scoring has been revised to reflect changes in symptom criteria based on Rome III. Some items included in the original QPGS for research purposes have been deleted from the QPGS-RIII for brevity (Caplan *et al.*, 2005). The 71-item QPGS was used to measure GI symptoms and categorizes functional GI disorders (FGIDs) per Rome-III criteria. For analysis, missing responses on the QPGS were interpreted as a lack of evidence for the assessed symptom. If eight or more items were missing, the QPGS was omitted from the analysis. (Gorrindo *et al.*, 2012)
- E. Dietary assessment
- A food frequency questionnaire (FFQ) and the 24-hour diet recall technique were used to examine diets. Based on the frequency of intake of a specified food list for a week, the FFQ was used to assess the typical dietary pattern, understand the quality of the diet, and predict obesity outcomes. Participants were asked to recollect their food intake in the preceding 24 hours for the 24-hour food recall (the previous day). Measuring cups were used to quantify the amount of food consumed. The amount of nutrients consumed was determined using the gram equivalents of various items.

3.10 Pretesting

Pretesting was done on 10 ASD children and their caretakers for the practicability and viability of the tool. The questionnaire was developed first in English and reviewed by the supervisor of the research. The draft sets of questionnaires and anthropometric instruments were pretested among the ASD children from the study site itself. This helped to achieve accuracy and clarity in the questionnaire, understand interviewing techniques as well as aid in standardization

procedures for anthropometry. After pre-testing all the ambiguous, misleading and wrongly interpreted questions were omitted and questionnaires were revised per the findings of pre-testing.

3.11 Validity and reliability of the study tools

Validity refers to the degree to which the data collection instruments will measure what they purposed to measure. The validity of the weighing balance was ascertained by comparing the data provided by the weighing balance with standard weights. Likewise, the validity of the stadiometer was ascertained by comparing the measurement from the stadiometer and the UNICEF stadiometer. The measuring tape was calibrated against a standard stadiometer. The instruments were checked and reset daily to validate the data. For 24-hour recall, different foods were standardized in measuring cups for data collection.

Reliability refers to the quality control measure of data collected. The questionnaire was also pre-tested before data collection to ascertain content reliability. The questionnaire was checked daily for completeness, consistency and clarity to respondents. The test re-test method was used to test the consistency of tools in producing the same results.

Part IV

Result and discussion

The study was carried out at the Autism Center Nepal, Avaani Foundation and Centre for Autism organizations in Kathmandu Valley which aim to provide care and educational facilities for children with autism in Nepal. The participants in the study were children and adolescents from 2-15 years of age. The results of the survey are presented in the following heading:

4.1 Socio-economic and demographic characteristics

Table 4.1(a) shows that out of 104 participants in the study, 58.7% of participants were from joint families whereas 41.3% were from nuclear families. Among 104 participants, 72.1% belonged to Khas-Arya ethnicity (Brahmin/Chettri) and 27.9% were Janjati.

Table 4.1 (a): Socio-demographic characteristics of the study population (n=104)

Variables	Frequency	Percentage
Family type		
Joint	61	58.7
Nuclear	43	41.3
Ethnicity		
Khas-arya	75	72.1
Janjati	29	27.9

As seen in Table 4.1 (b), business/employment accounted for 91.3% of all fathers' occupations, followed by foreign employment at 8.7%. The majority of the fathers in the survey were educated, with 8.7% who completed the secondary level, 21.2% who had completed the higher secondary level and the remaining 70.2% who had completed the university level. The majority of families in the sample, or 86.5%, had monthly incomes of more than 30,000, and 13.5% had monthly incomes between Rs.20,000 and 30,000, according to the study. Mothers were more likely than fathers to be active in purchasing food in the study's sample households, with a percentage of 69.2% versus 14.4%.

Table 4.1 (b): Socio-economic and demographic characteristics of the study population
(n=104)

Variables	Frequency	Percentage
Father's education		
Secondary	9	8.7
Higher secondary	22	21.2
University	73	70.2
Father's occupation		
Business/Employment	95	91.3
Foreign employment	9	8.7
Monthly income classification		
Above 30,000s	90	86.5
20,000 to 30,000	14	13.5
Household food purchaser		
Mother	72	69.2
Father	15	14.4
Both	17	16.3

4.2 Child characteristics

According to Table 4.2 of the study, out of 104 participants, 77.9% of the participants were male and 22.1% were female. According to estimates, males are three to four times more likely than girls to have autism (Lyen, 2023). The children were categorized into 4 groups as 2-4 years of age, 5-9 years of age, 10-14 years of age and 15-18 years of age. The majority of participants were in the age group 2-4 years i.e. 59.6% followed by 35.6% in the 5-9 year group, 3.8% in the 10-14 year group and 1% in the 15-18 year group. Among 104 participants,

firstborns made up 66.3% of the survey population whereas 33.7% were secondborns or thirdborns. While 83.7% of participants had a birth weight of more than 2.5 kg, just 16.3% of participants had a birth weight of less than 2.5 kg.

Table 4.2: Child characteristics of the study population (n=104)

Variables	Frequency	Percentage
Gender		
Male	81	77.9
Female	23	22.1
Age		
(1-3) years of age	30	28.8
(4-6) years of age	65	62.5
(7-9) years of age	4	3.8
(10-12) years of age	3	2.9
(13-15) years of age	2	1.9
Birth order		
First	69	66.3
Second/Third	35	33.7
Birth weight		
Less than 2.5 kg	17	16.3
More than 2.5 kg	87	83.7

4.3 Child caring practices

As shown in Table 4.3 (a), among 104 participants, 92.3% were reported to be breastfed after birth. Among 97 participants who were breastfed after birth, 33% were reported to be breastfed within 1 hour of birth, 17.5% were fed within 8 hours of birth, 16.5% were fed within 24 hours

of birth and 33% were fed only after 24 hours. The participants who were fed with the first milk or colostrum were 85.6%. About 9.3% of participants were breastfed less than 8 times a day, 38.1% were fed 8-10 times a day whereas 52.6% were fed 11-12 times a day.

Table 4.3 (a): Child caring practices of the study population (n=104)

Variables	Frequency	Percentage
Breastfeeding after birth		
Yes	97	93.3
No	7	6.7
Initiation of breastfeeding (n=97)		
Within 1 hour	32	33
Within 8 hours	17	17.5
Within 24 hours	6	16.5
After 24 hours	32	33
Colostrum feeding		
Yes	89	85.6
No	15	14.4
Breastfeeding frequency (n=97)		
Less than 8 times a day	9	9.3
About 8-11 times a day	37	38.1
More than 12 times a day	51	52.6

Only 49% of the participants were exclusively breastfed for the first 6 months as compared to 51% who were not. When asked for the reasons for non-exclusive breastfeeding of the participants, 87.7% said it was due to insufficient milk production, 1.8% said it was due to medical complications and 10.5% gave other reasons such as work obligations, going abroad,

etc. On assessing the breastfeeding status of the population, 4.1% of participants were found to be continuing to receive breast milk while 95.9% have stopped receiving their mother's breast milk. Among the 93 participants who had stopped receiving breast milk, 79.6% of participants were breastfed before 2 years of age and 20.4% of participants were breastfed above 2 years of age.

Table 4.3 (b): Child caring practices of the study population (n=104)

Variables	Frequency	Percentage
Exclusive breastfeeding		
Yes	51	49
No	53	51
Reasons for non-exclusive breastfeeding (n=53)		
Not sufficient milk production	50	87.7
Medical complication	1	1.8
Breastfeeding status (n=97)		
Still breastfeeding	4	4.1
Stopped breastfeeding	93	95.9
Age at which breastfeeding was stopped (n=93)		
Before 2 years of age	58	62.4
After 2 years of age	35	37.6

As shown in Table 4.3 (c), participants who received pre-lacteal feeds were 7.7%. A majority of 69.2% of participants were said to be bottle-fed mostly due to insufficient milk production. Mothers who knew how to prepare lito was 99%. More than half of the participants (56.7%) were not toilet trained in the study. Individuals with developmental disabilities such as autism spectrum disorder (ASD) are more likely to experience toileting problems, more so than the general population (Matson *et al.*, 2011). All the participants in the study had completed vaccination and received Vitamin A and deworming tablets.

Table 4.3 (c): Child caring practices of the study population (n=104)

Variables	Frequency	Percentage
Received pre-lacteal feeds		
Yes	8	7.7
No	96	92.3
Bottle feeding		
Yes	72	69.2
No	32	30.8
Knowledge of the preparation of lito		
Yes	103	99
No	1	1
Toilet trained		
Yes	45	43.3
No	59	56.7
Completed vaccination of the child		
Yes	104	100
No	0	0
Intake of vitamin A and deworming tablet		
Yes	104	100
No	0	0

4.4 Maternal characteristics

As seen in table 4.4 (a), the highest percentage of mothers were found to have gained education up to university level i.e. 67.3% followed by 23.1% up to higher secondary level and 9.6% up

to secondary level. The maximum number of mothers were found to be homemakers i.e. 50% followed by 45.2 who were job holders or involved in business and 4.8% were in foreign employment. From the study group, 17.3% of mothers were married before the age of 20 years, and 82.7% were married after the age of 20 years. Similarly, the study found that 20.2% of mothers had their first pregnancy before the age of 20 years and 79.8% had their first pregnancy after the age of 20 years.

Similarly, the percentage of women who took iron and folate tablets during pregnancy was found to be 99% and among them, 47.6% started the intake during the first trimester and 52.4% started the intake during the second trimester.

When asked about malnutrition, 95.2% responded as they have some idea about the term and 4.8% said they do not know about malnutrition as shown in Table 4.4 (b). Among those who had heard about malnutrition, 97% said that it was caused by less intake of food by the child.

In the study, 50% of mothers reported that they used to consume more than the usual amount of food during pregnancy, 19.2% said their intake was less than usual and 30.8% said that their food intake was as usual. The frequency of eating food less than 3 times was found in 7.7% of mothers, 69.2% reported they ate 3-4 times a day and 23.1% ate more than 4 times a day during their pregnancy.

Table 4.4 (a): Maternal characteristics of the study population (n=104)

Variables	Frequency	Percentage
Mother's education		
Primary/Secondary	10	9.6
Higher Secondary	24	23.1
University	70	67.3
Mother's occupation		
Business/Employment	47	45.2
Foreign employment	5	4.8
Housewife	52	50
Age at marriage		
Before 20 years	18	17.3
Above 20 years	86	82.7
Age at first pregnancy		
Before 20 years	21	20.2
Above 20 years	83	79.8
Intake of iron and folate tablets		
Yes	104	100
No	-	-
Initiation of intake (n=103)		
1 st trimester	49	47.6
2 nd trimester	54	52.4
3 rd trimester	0	0

Table 4.4 (b): Maternal characteristics of the study population (n=104)

Variables	Frequency	Percentage
Knowledge on malnutrition		
Yes	99	95.2
No	5	4.8
Cause of malnutrition (n=99)		
Less food intake	96	97
Don't know	3	3
More than 4 times a day	24	23.1
Amount of food intake during pregnancy		
More than usual	52	50
Less than usual	20	19.2
As usual	32	30.8
Frequency of food intake during pregnancy		
Less than 3 times a day	8	7.7
About 3-4 times a day	72	69.2
More than 4 times a day	24	23.1

4.5 Prevalence of malnutrition

Anthropometric indices are the major tools for the assessment of nutritional status of children. The indices obtained were weight for age (underweight), height for age (stunting) and BMI for age (thin, overweight and obesity) to assess the prevalence of nutritional status of the study participants.

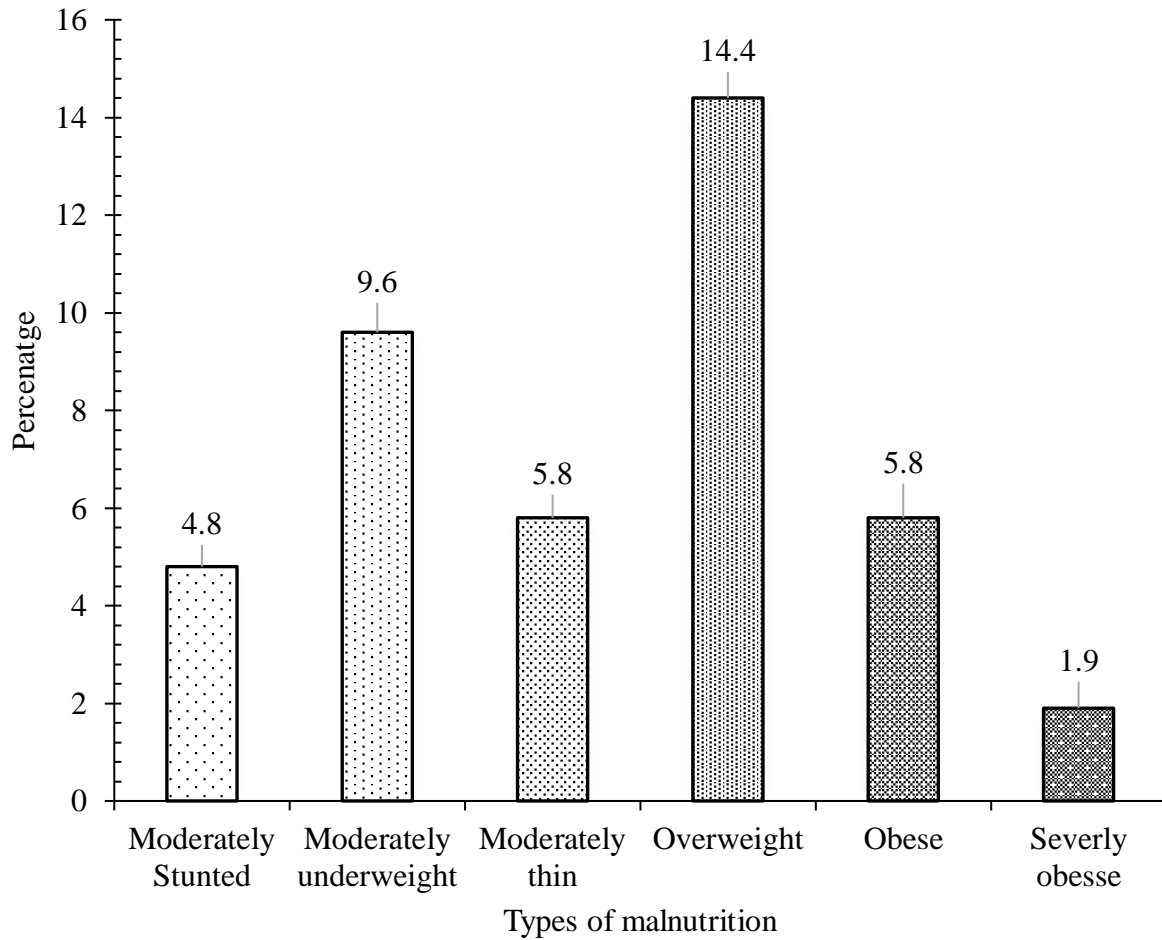


Figure 4.1: Prevalence of underweight, stunting, thinness, overweight and obesity among the survey population

The overall magnitudes of malnutrition among the study population were 4.8% and 9.6% for moderately underweight and moderately stunting respectively as shown in Figure. Similarly, 5.8% of autistic participants were found to be moderately thin, 14.4% were found to be overweight, 5.8% were obese and 1.9% were severely obese.

In a study among autistic children in Oman (Al-Farsi *et al.*, 2011a) the prevalence of underweight and stunting was found to be 3.9% and 2.3% respectively. Stunting rates were found to be lower than that of the present study. In the present study, more autistic children were found to have a higher BMI for their age and were overweight and obese. Several studies have revealed that the prevalence of obesity and overweight is significantly greater among children with autism compared to the general population (Curtin *et al.*, 2005; Memari *et al.*, 2012; Kamal *et al.*, 2019). The higher prevalence of overweight and obesity suggest that overnutrition was more prevalent than undernutrition (Eow *et al.*, 2021).

4.5.1 Distribution of malnutrition based on gender

Males had a greater prevalence of being underweight (4%) than females (1%). Stunting rates were also higher in males than in females, 7.7% versus 1.9%. The proportion of underweight and stunting was also found to be higher in males than in females by Al-Farsi *et al.* (2011a). However, this difference in the recent study may be due to a higher number of males than females.

2% of females and 3.8% of males were found to be moderately thin. More males than females were discovered to be overweight. 3.8% of the males and 2% of the females were found to be overweight. Similar findings were also found to be higher in males in a study conducted in Malaysia by (Eow *et al.*, 2021). The percentage of severely obese males was found to be 1.9%, while there were no obese females.

Table 4.5: Distribution of malnutrition based on the gender of the study population (n=104)

	Characteristics	Male (%)	Female (%)	All (%)
WAZ (below 11 years)	Moderately underweight	4	1	5
	Normal	73	22	95
HAZ	Moderately stunted	7.7	1.9	9.6
	Normal	70.2	20.2	90.4
BAZ	Moderately thin	3.8	2	5.8
	Normal	53.8	18.3	72.1
	Overweight	14.4	-	14.4
	Obese	3.8	2	5.8
	Severely obese	1.9	-	1.9

4.5.2 Distribution of malnutrition based on Age

As seen in Table 4.6 (a), stunting (6) and underweight (4) was found to be more prevalent in the 4-6 age group as compared to the other groups. In the 7-9 and 13-15 age groups, no

participants were found to be underweight or stunted. In the 10-12 age group only one child was found to be moderately stunted.

Table 4.6 (a): Distribution of WAZ and HAZ based on the age of the study population (n=104)

Age group (years)	N	WAZ		HAZ	
		<-3	<-2	<-3	<-2
(2-3)	30	-	1 (3.3%)	-	3 (10%)
(4-6)	65	-	4 (6.2%)	-	6 (9.2%)
(7-9)	4	-	-	-	-
(10-12)	3	-	-	-	1 (33.3%)
(13-15)	2	-	-	-	-

Similarly as shown in Table 4.6 (b), in the 4-6 age group, more children were found to be moderately thin (3), overweight (9) and obese (3). One child was found to be severely obese in (2-3), (4-6) and (13-15) age groups, each.

In a study by (Hyman *et al.*, 2012) more number of autistic children aged 2-5 were more likely to be overweight which is similar to the findings of the given study.

Table 4.6 (b): Distribution of BAZ based on the age of the study population (n=104)

Age group (years)	N	BAZ				
		<-3	-3 to -2	+1 to +2	+2 to +3	>+3
(2-3)	30	-	1 (3.3%)	4 (13.3%)	2 (6.7%)	1 (3.3%)
(4-6)	65	-	3 (4.6%)	9 (13.8%)	3 (4.6%)	1 (1.5%)
(7-9)	4	-	2 (50%)	-	-	-
(10-12)	3	-	-	1 (33.3%)	1 (33.3%)	-
(13-15)	2	-	-	-	-	1 (50%)

4.5.3 Nutritional status in comparison with WHO standard

4.5.3.1 Nutritional status of 2 to 5 year autistic children

Distribution of underweight, stunting and BMI-for-age among autistic children 2 to 5 years of age based on WHO standards are shown in the figures below respectively.

a. Weight for age

The percentage of participants in this age group, who were moderately underweight was found to be 4.5% out of which all were males. In a study carried out in Oman, the prevalence of underweight was found to be 3.9% (Al-Farsi *et al.*, 2011a), which is slightly less than that of the present study.

The mean weight for the age z-score of the children in this age group was found to be -0.09, which is less than the reference to the standard. The curve in the figure is skewed slightly to the left side of the WHO standard curve showing a slight prevalence of underweight among the study population.

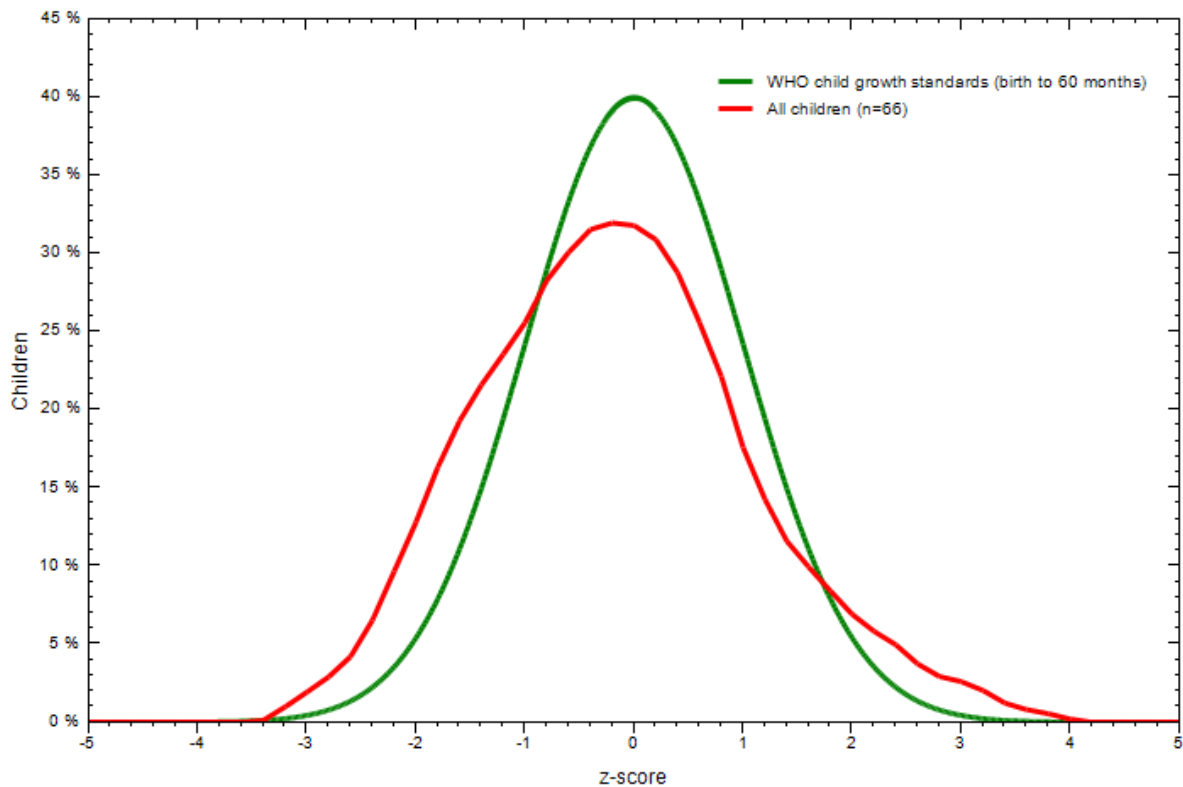


Figure 4.2: Distribution of underweight among 2 to 5 years old children based on WHO standard (n=66)

b. Height for age

The prevalence of moderate stunting was found to be 9.09% out of which 7.58% and 1.51% were males and females respectively. In a study conducted in Malaysia, (Eow *et al.*, 2021) out of 224 children aged between 3-7 years old, 8% of children were found to be stunted which is similar to the finding in this study. However in other studies, (Al-Farsi *et al.*, 2011a; Waly, 2014) the prevalence of stunting was found to be 2.3%.

The mean height for the age z-score of the children in this age group was found to be -0.17, which is less than the reference to the WHO standard. The curve in the figure is skewed slightly to the left side of the WHO standard curve showing the slight prevalence of stunting among the study population.

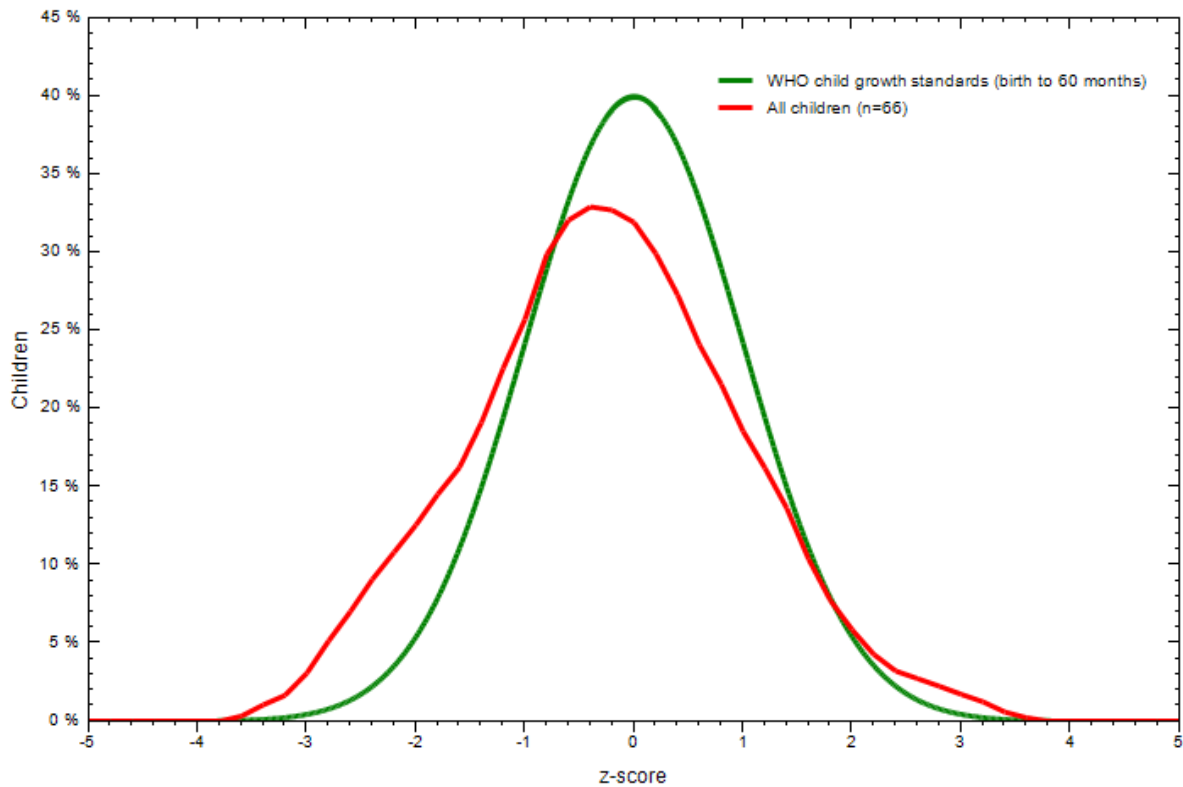


Figure 4.3: Distribution of stunting among 2 to 5 years old children based on WHO standard (n=66)

c. BMI for age

Out of 66 respondents in this age group, 3.03% and 16.67%, all males, were found to be moderately thin and overweight respectively. Xiong *et al.* (2009) and Curtin *et al.* (2005) and also found the prevalence of overweight to be 17% and 14.2% which is similar to the shown data.

Similarly, 4.54% of respondents were found to be obese while 3.03% were found to be severely obese. In a study of 224 children aged (3-7) conducted by Eow *et al.* (2021), the prevalence of obesity and severely obese was found to be 6.3% and 4.5% respectively which corresponds to the given findings.

The mean BMI for the age z-score of the children in this age group was found to be 3.32, which is more than the reference to the WHO standard. The curve in the figure is slightly skewed to the left side of the WHO standard curve and a slight portion of the curve is also skewed to the right side of the standard curve showing the prevalence of both thinness and overweight

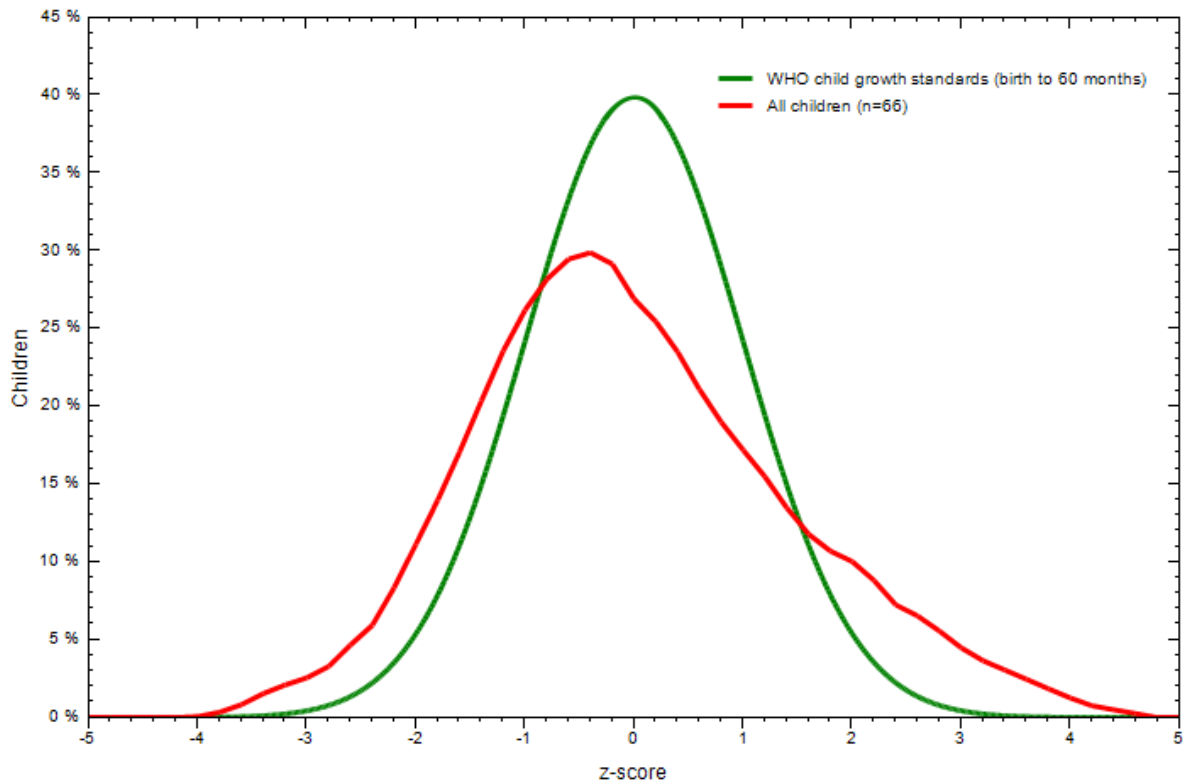


Figure 4.4: Distribution of BMI-for age among 2 to 5 years of age children based on WHO standard (n=66)

4.5.3.2 Nutritional status of 5 to 19 years autistic children

a. Weight for age

6.25% of participants in this age group were found to be underweight, out of which the proportions of males and females were equal. In a study carried out in Iran (2010) among 113 children of age 7 to 14 years, the prevalence of underweight was found to be 8.7% (Memari *et al.*, 2012).

The mean Weight for age z-score of children in this age group was found to be -0.53, which is less than the reference to the WHO standard. The curve in the figure is skewed to the left side of the WHO standard curve showing a prevalence of underweight in this age group.

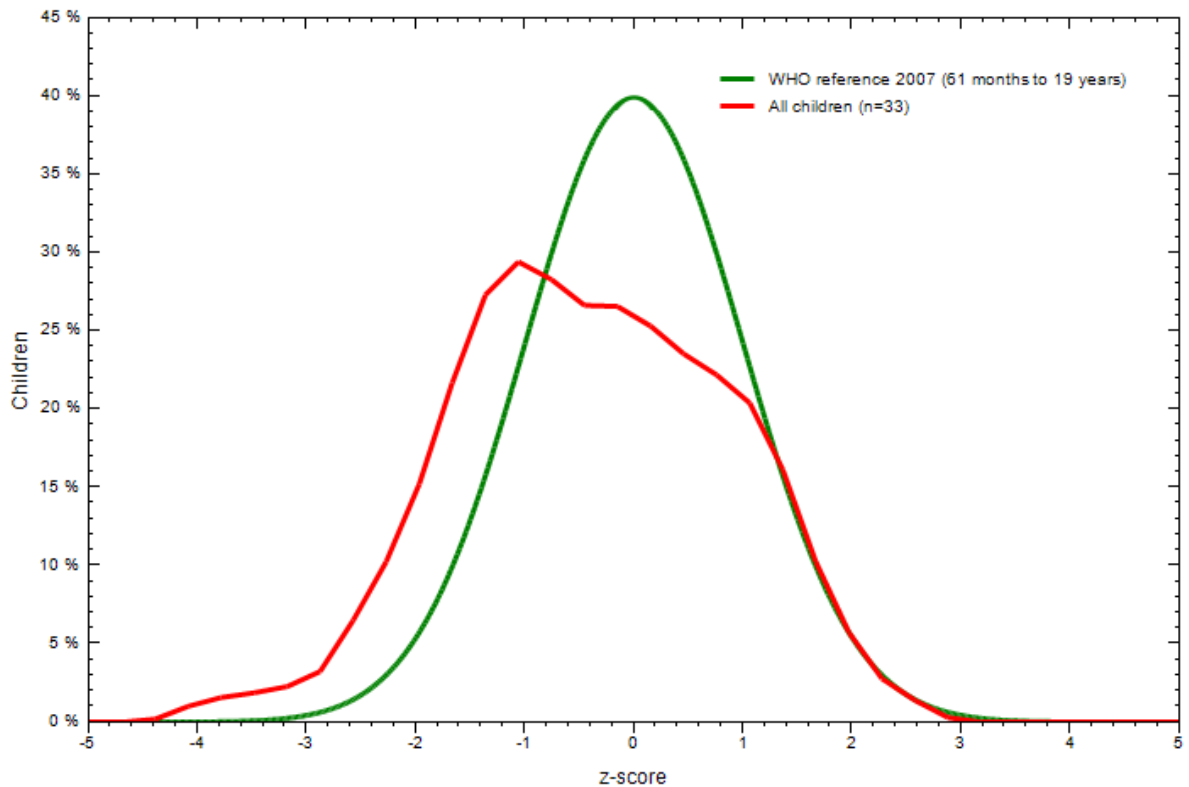


Figure 4.5: Distribution of underweight among 5 to 19 year old children based on WHO standard (n=38)

b. Height for age

Out of 38 participants, 10.53% were found to be moderately stunted out of which 2.63% were females and 7.89% were males. In a study carried out in China, stunting was found to be 7.14% (Liu *et al.*, 2016a), which is slightly less than that of the present study.

The mean Height for age z-score of the children in this age group was found to be -0.56 which is less than the reference to WHO standard. The curve in the figure is more skewed to the left with a slight portion skewed to the right of the WHO standard curve showing the prevalence of underweight in this age group.

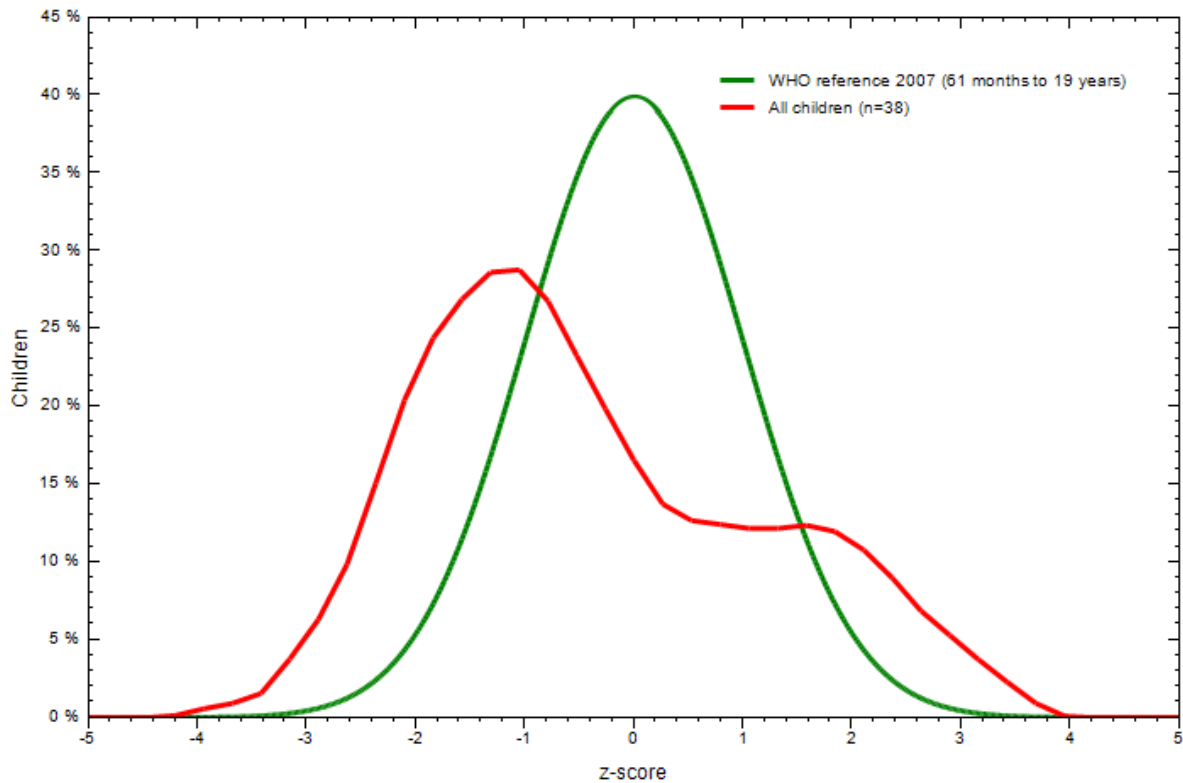


Figure 4.6: Distribution of stunting among 5 to 19 year old children based on WHO standard (n=38)

c. BMI for age

The percentage of participants who were found to be moderately thin was found to be 10.53% in which there is an equal proportion of males and females. Similarly, 10.53% were found to be overweight, out of which all were males. A study conducted by (Marí-Bauset *et al.*, 2015) found that 10% of children with autism were overweight which is similar to the given findings. Another study by (Hyman *et al.*, 2012) also found 11% of children aged 2-11 years were overweight however 16% of children were found to be obese which is higher than the findings of this study i.e. 7.89%.

The mean BMI-for-age z-score of the autistic children in this age group was found to be -0.11 which is less than the reference to the WHO standard. The curve in the figure is skewed to the left side of the WHO standard curve and a slight portion of the curve is also skewed to the right side of the standard curve showing the prevalence of both thinness and overweight in this age group.

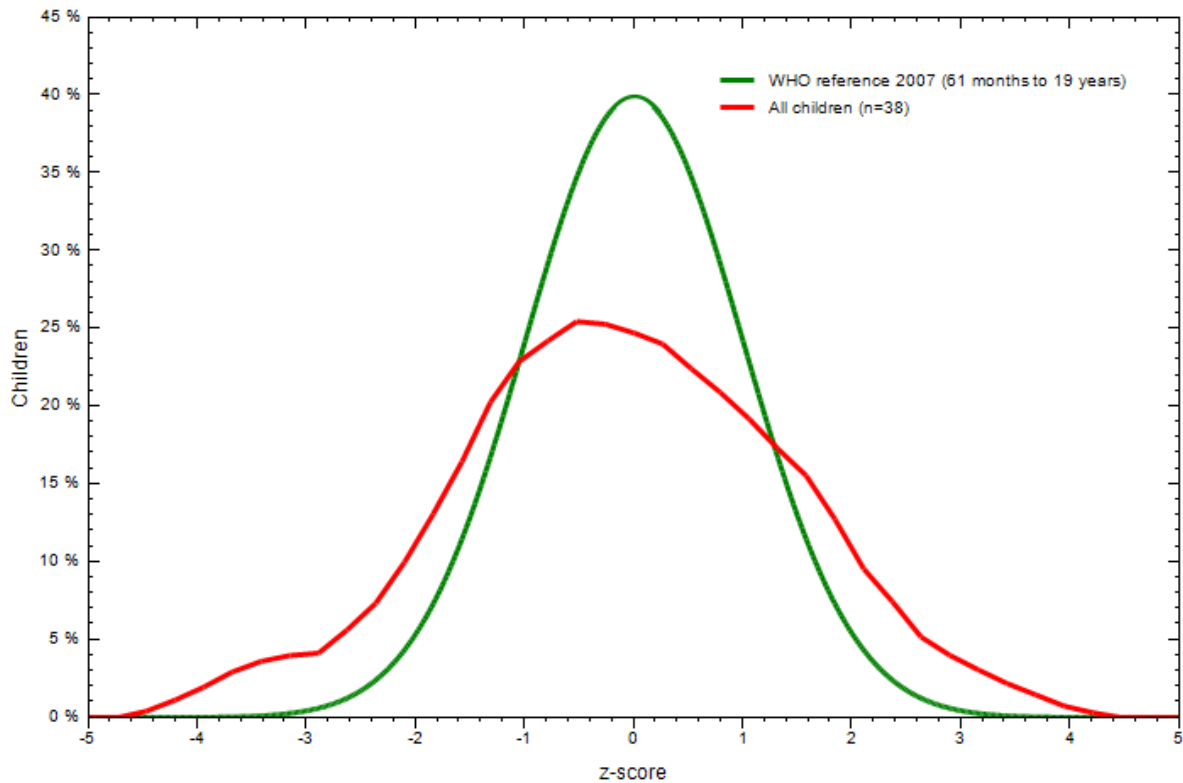


Figure 4.7: Distribution of BMI-for-age among 5 to 19 year old autistic children based on WHO standard

4.6 Food frequency questionnaire

As shown in Table 4.12, among cereal products, rice was regularly consumed by 98% of the participants in the study population while 26% and 21.2% consumed wheat and maize/millet/barley and its products respectively. The regular consumption of daal was found to be 90.4%. About 41.3% of children regularly consumed green leafy vegetables while 8.7% said they dislike them. A majority (64.4%) of children consumed fruits regularly which is higher than the consumption of vegetables.

The study showed that the regular consumption of milk was very high i.e. 76% whereas 14.4% said that they disliked milk and wouldn't eat it. The consumption of different kinds of meat was found to be low with the majority of the participants only consuming it rarely. The regular consumption of eggs was found to be 41.3% while 28.8% said they disliked eggs. Majority of the respondents consumed processed/fast foods with 17.3% consuming it regularly, 54.8% consuming it frequently and 26% consuming it on a rare basis.

Table 4.7: Distribution of food intake (n=104)

Variables	Frequency of food consumption			
	Regular	Frequent	Rare	Never
Rice	102 (98%)	1 (1%)	1 (1%)	-
Wheat	27 (26%)	32 (30.8%)	32 (30.8%)	13 (12.5%)
Maize/Millet/Barley	22 (21.2%)	29 (27.9%)	35 (33.7%)	18 (17.3%)
Daal	94 (90.4%)	7 (6.7%)	3 (2.9%)	-
Grams/Beans/Peas	7 (6.7%)	37 (35.6%)	47 (45.2%)	13 (12.5%)
Green leafy vegetables	43 (41.3%)	33 (31.7%)	19 (18.3%)	9 (8.7%)
Other vegetables	58 (55.8%)	28 (26.9%)	13 (12.5%)	5 (4.8%)
Roots and tubers	15 (14.4%)	25 (24%)	34 (32.7%)	30 (28.8%)
Fruit	67 (64.4%)	16 (15.4%)	12 (11.5%)	9 (8.7%)
Milk	79 (76%)	5 (4.8%)	5 (4.8%)	15 (14.4%)
Curd	11 (10.6%)	13 (12.5%)	32 (30.8%)	48 (46.2)
Ghee/butter	70 (67.3%)	8 (7.7%)	9 (8.7%)	17 (16.3%)
Paneer/Cheese	4 (3.8%)	12 (11.5%)	39 (37.5%)	49 (47.1%)
Chicken	6 (5.8%)	31 (29.8%)	38 (36.5%)	29 (27.9%)
Fish	-	4 (3.8%)	26 (25%)	74 (71.2%)
Red meat	1 (1%)	7 (6.7%)	43 (41.3%)	53 (51%)
Egg	43 (41.3%)	25 (24%)	6 (5.8%)	30 (28.8%)
Processed food	18 (17.3%)	57 (54.8%)	27 (26%)	2 (1.9%)

4.7 Dietary intake

The study found that the average calorie intake was 1349.63 ± 459.43 Kcal per day for children 2-3 years of age which was 121.59% of RDA. Similarly average protein (44.39 ± 19.47 g/day), total fat (49.33 ± 18.69 g/day), calcium (549.61 ± 356.73 mg/day) and iron (8.14 ± 3.67 mg/day) intake were 3.55%, 197.32%, 109.92% and 101.75% of RDA respectively.

Differences between mean calcium and iron intake with their respective RDA were statistically not significant ($p > 0.05$) while mean calorie, protein and total fat intake to RDA was statistically significantly higher ($p < 0.05$).

Table 4.8: Nutrient intake by 2-3 year old autistic children (n=30)

	Intake	RDA	% of RDA	T	P-value
Calories (Kcal/day)	1349.63 ± 459.43	1110	121.59%	2.857	0.008*
Protein (g/day)	44.39 ± 19.47	12.5	355.12%	8.974	0.000*
Total fat (g/day)	49.33 ± 18.69	25	197.32%	7.129	0.000*
Calcium (mg/day)	549.61 ± 356.73	500	109.92%	0.762	0.452
Iron (mg/day)	8.14 ± 3.67	8	101.75%	0.203	0.841

Average daily caloric intake (1627.69 ± 481.01 Kcal) for children aged 4-6 was found to be 119.68% of RDA, while intakes of total fat and protein were correspondingly 318.06% and 216.08%. The average daily consumption of calcium and iron was 120.79% of RDA and 86% of RDA, respectively.

The difference between mean calorie, protein, total fat and calcium with their respective RDA was found to be significantly higher ($p < 0.05$) whereas the iron with their respective RDA was found to be significantly lower ($p < 0.05$).

Table 4.9: Nutrient intake by 4-6 year old autistic children (n=65)

	Intake	RDA	% of RDA	T	P-value
Calories (Kcal/day)	1627.69±481.01	1360	119.68%	4.487	0.000*
Protein (g/day)	50.89±18.15	16	318.06%	15.495	0.000*
Total fat (g/day)	54.02±17.36	25	216.08%	13.479	0.000*
Calcium (mg/day)	664.36±364.88	550	120.79%	2.527	0.014*
Iron (mg/day)	9.46±3.13	11	86%	-3.973	0.000*

Intake of 1459.03±442.94 Kcal per day, the average for children aged 7-9, was found to be 85.24% of the RDA. The average protein intake and total fat intake of children in this age range were also found to be 196.65% and 185.13% of RDA, respectively. It was found that the average daily consumption of calcium and iron was 106.74% and 60.2% of RDA, respectively. The difference between mean calorie, protein calcium and iron with their respective RDA was found to be statistically not significant ($p>0.005$) whereas the difference between mean daily total fat intake with their respective RDA was found to be significantly higher ($p>0.05$)

Table 4.10: Nutrient intake by 7-9 year old autistic children (n=4)

	Intake	RDA	% of RDA	T	P-value
Calories (Kcal/day)	1449.03±442.94	1700	85.24%	-1.133	0.34
Protein (g/day)	45.23±15.48	23	196.65%	2.873	0.064
Total fat (g/day)	55.54±7.97	30	185.13%	6.410	0.008*
Calcium (mg/day)	693.82±203.81	650	106.74%	0.430	0.696
Iron (mg/day)	9.03±7.69	15	60.2%	-1.553	0.218

The average daily caloric intake for participants aged 10 to 12 was found to be 1818.32±278.13 Kcal or 81.91% of the RDA. The corresponding percentages of protein and total fat intake were respectively 156.38% and 1% of the RDA. It was shown that the average intake of calcium and

iron was 49.19% and 57.38% of RDA, respectively. The difference between the mean calorie, protein, fat, calcium and iron intake with their respective RDA was found to be statistically insignificant ($p>0.005$)

Table 4.11: Nutrient intake by 10-12 year old autistic children (n=3)

	Intake	RDA	% of RDA	T	P-value
Calories (Kcal/day)	1818.32±278.13	2220	81.91%	-2.501	0.129
Protein (g/day)	50.04±13.01	32	156.38%	2.403	0.138
Total fat (g/day)	59.11±21.63	35	168.89%	1.930	0.193
Calcium (mg/day)	418.08±403.85	850	49.19%	-1.852	0.205
Iron (mg/day)	9.18±6.92	16	57.38%	-1.708	0.203

The study found that participants aged 13 to 15 had an average daily caloric intake that was 5.89% of RDA. Similarly, it was shown that the average daily intake of protein and fat was 113.56% of RDA and 95.89% of RDA, respectively. Children in this age range had daily averages of 53.31% and 52.32% of the recommended amounts of calcium and iron, respectively. The difference between mean protein, total fat and calcium with their respective RDA was found to be statistically insignificant ($p>0.005$) whereas the difference between mean calorie and iron intake with their respective RDA was found to be statistically lower ($p>0.005$).

Table 4.12: Nutrient intake of 13-15 year old autistic children (n=2)

	Intake	RDA	% of RDA	T	P-value
Calories (Kcal/day)	1655.56±83.52	2860	57.89%	-20.395	0.031*
Protein (g/day)	51.1±2.23	45	113.56%	3.876	0.161
Total fat (g/day)	43.15±9.16	45	95.89%	-0.285	0.823
Calcium (mg/day)	533.06±219.42	1000	53.31%	-3.01	0.204
Iron (mg/day)	11.51±0.45	22	52.32%	-32.868	0.019*

The autistic participants of the study were compared with RDA values by NIN for percent intake of calories, protein, fat, calcium and iron as shown in Table 4.12. The RDA is set at an intake level that exceeds the requirement of 97%–98% of individuals. Using 77% of the RDA as a cutoff value provides a conservative estimate of nutrient inadequacy based on a coefficient of variation for the nutrient of 15% about the Estimated Average Requirement (R.S. Gibson, 2005a). Overall, the study demonstrates that out of 104 study subjects, the mean calorie (44.2%), protein (96.2%) and total fat (81.73%) were found to be above 120% of RDA where the mean calcium (45.2%) and iron (80.8%) intake was found to be below 80% of RDA.

The energy intake among autistic children is higher by previous studies (Souza *et al.*, 2012; Arija *et al.*, 2022). In a study by Levy *et al.* (2007a), among 52 ASD children aged between 3 and 8 years, the majority of the subjects had protein intake above 120% of RDA. The mean intake of total fat was found to be higher among autistic children in a study in Spain (Marí-Bauset *et al.*, 2016). The high fat intake among autistic children in the recent study may be due to the regular consumption of ghee reported in the FFQ.

Similarly, the study shows that there is more occurrence of micronutrient deficiency i.e. calcium and iron among autistic children. Siddiqi *et al.* (2019a) and (Xia *et al.*, 2010) also found the intake of calcium and iron intakes was insufficient among the majority of the subjects.

Table 4.13: Nutrient intake of study subjects as a percentage of RDA

	<80% of RDA	>120% of RDA
Calories (Kcal/day)	18.3%	44.2%
Protein (g/day)	-	96.2
Total fat (g/day)	7.69	81.73
Calcium (mg/day)	45.2	32.7
Iron (mg/day)	80.8	9.6

4.8 Mealtime behaviour problem

According to Table 4.13, the majority of the study subjects i.e. 43.3% rarely cry or scream during meals, and 35.6% rarely turn their faces or bodies away from the food. The study

showed that 38.5% of children rarely expel food that they have eaten and 46.2% never engaged in disruptive behaviour (pushing/throwing utensils) at mealtimes. Similarly, when food is presented, 33.7% of kids rarely close their mouths tightly.

Regarding features of autism, just 4.8% of children remain seated throughout their, compared to 30.8% of children who do not. 50% of the study's participants never showed aggressive behaviour (punching, kicking, or scratching others) and 62.5% never engaged in self-harming behaviour during mealtimes (such as punching or biting oneself). The majority of children, or 46.2% of children, were found to be occasionally flexible with mealtime schedules. Food that needs a lot of chewing is rarely refused by about 37.5% of children, and it is occasionally refused by about 28.8% of children.

Under the limited variety of the BAMBI questionnaire, 31.7% of children were rarely willing to eat new foods and 43.3% occasionally disliked certain foods and wouldn't eat them. 42.3% seldom preferred the same food at each meal while 36.5% rarely accepted or preferred variety of food. The majority of children i.e. 39.4% occasionally preferred crunchy foods. 47.1% and 35.6% of children in the study never preferred to have their food served and prepared in a particular way respectively. A majority of children i.e. 33.7% preferred only sweet foods often at almost every meal.

Table 4.14: Mealtime behaviour of the study population (n=104)

Mealtime behaviour	Never (%)	Rarely (%)	Seldom (%)	Occasionally (%)	Often at almost every meal (%)
Food refusal					
Crying, screaming	18.3	43.3	19.2	14.4	4.8
Turing face, body	14.4	20.2	35.6	22.1	7.7
Expel out food	10.6	38.5	31.7	13.5	5.8
Showing disruptive behaviour	46.2	25	21.2	5.8	1.9
Closing mouth tightly	29.8	33.7	23.1	12.5	1
Features of autism					

Remains seated	4.8	19.2	14.4	30.8	30.8
Shows aggressive behaviour	50	30.8	11.5	6.7	1
Shows self-injurious behaviour	62.5	27.9	3.8	2.9	2.9
Flexible about mealtime routines	1.9	15.4	16.3	46.2	20.2
Refuses food that requires a lot of chewing	2.9	37.5	19.2	28.8	11.5
Limited variety					
Willing to try new foods	9.6	31.7	26	26.9	5.8
Dislikes certain foods	4.8	5.8	23.1	43.3	23.1
Prefers same food	12.5	28.8	42.3	15.4	1
Prefers crunchy foods	-	5.8	23.1	39.4	31.7
Accepts or prefers a variety of food	3.8	36.5	25	26.9	7.7
Prefers to have food served in a particular way	47.1	36.5	7.7	6.7	1.9
Prefers only sweet foods	-	11.5	25	29.8	33.7
Prefers food prepared in a particular way	35.6	41.3	6.7	10.6	5.8

Every behaviour listed on the BAMBI was regarded as problematic by the parents. The percentages of the behaviours regarded by parents as problematic are shown in Figure. The top 5 problematic mealtime behaviour were: disliking certain food and won't eat them (79.8%), turning his/her face or body away from food (60.6%), preferring only sweet food (58.7%), preferring the same food at each meal (48.1%), not willing to try new foods (47.1%) and not accepts or prefers a variety of food (47.1%).

Similar to the results reported by previous studies (Lockner *et al.*, 2008; Bandini *et al.*, 2010) parents of autistic children in this study identified food selectivity features such as disliking certain foods and not eating them, not willing to try new foods and not accepting or preferring a variety of food as major problems. Similarly, Provost *et al.* (2010) also reported problematic behaviour of children with autism repetitively eating the same foods (42%).

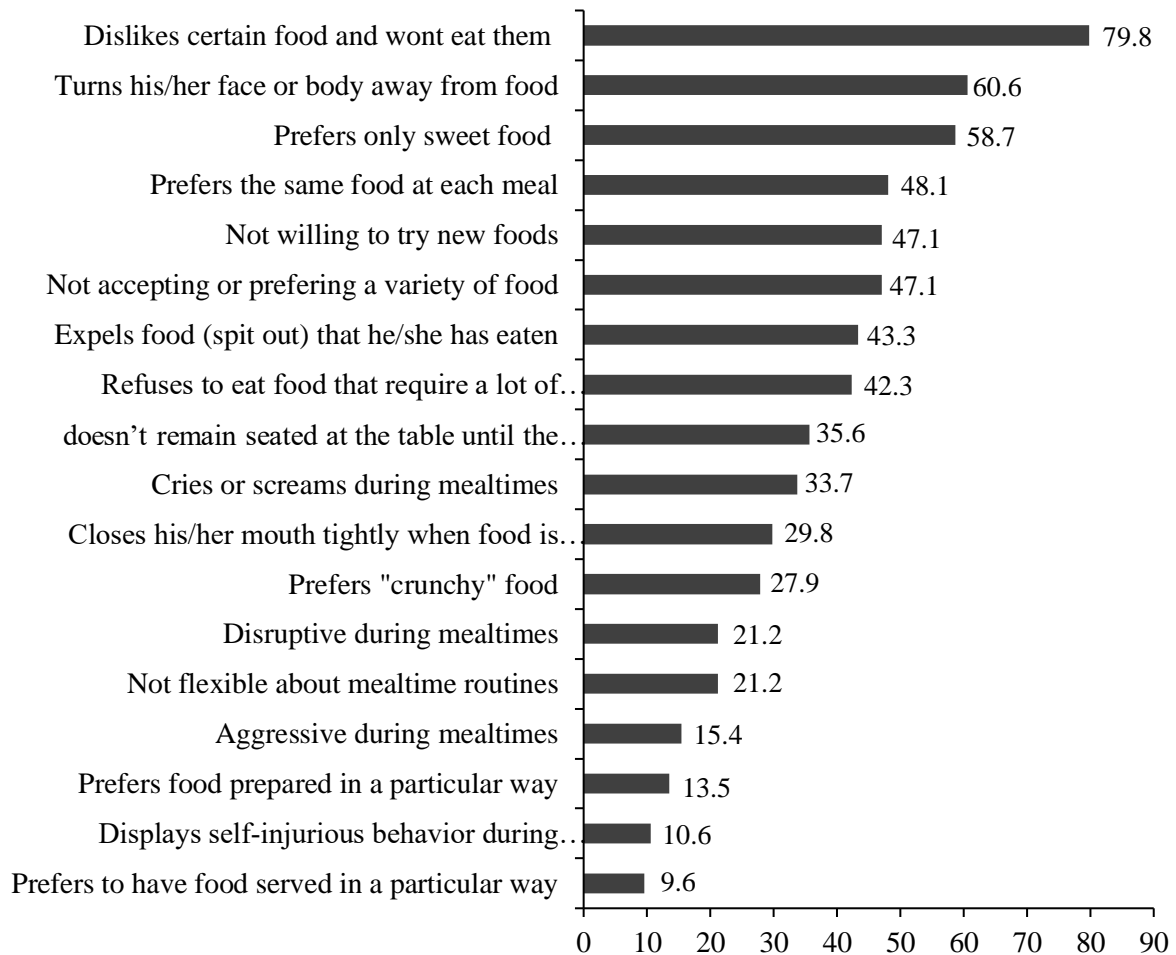


Figure 4.8: Problematic mealtime behaviours identified by caretakers of the children in the study

4.9 Rome III Diagnostic Questionnaire for the Pediatric Functional GI Disorders

From the Questionnaire on Pediatric Gastrointestinal Symptoms—Rome III Version the most common type of functional GI disorder found was functional constipation (33.7%) followed by nonretentive faecal incontinence (7.7%) and irritable bowel syndrome 4.8%). The remaining disorders given in the questionnaire (functional dyspepsia, abdominal migraine, functional abdominal pain, aerophagia, cyclic vomiting syndrome and adolescent rumination syndrome), were not found in any of the autistic children in the recent study.

In a study among autistic children aged 5-19 years, using the QPGS-RIII, functional constipation (44.7%) was the most common FGID found (Gorrindo *et al.*, 2012). Another study found 39% and 2.44% of autistic children with functional constipation and nonretentive faecal incontinence.

Many of the children in the study were not toilet trained which may be one of the reasons for the higher number of children found to have constipation and nonretentive faecal incontinence as the toilet training phase, which is known to be a potentially crucial stage in the development of functional defecation disorders (constipation and nonretentive faecal incontinence), may instead be complicated by behavioural issues, children with ASD's aversion to change, and difficulties learning new skills (Borowitz *et al.*, 2003).

Table 4.15: Prevalence of Functional GI disorders in the study population who were above 4 years (n=74)

Functional GI disorder	Frequency	Percentage
Functional constipation	35	33.7
Nonretentive faecal incontinence	8	7.7
Irritable bowel syndrome	5	4.8

4.10 Factors affecting malnutrition

Malnutrition was assessed by underweight, stunting and thinness/obesity. The factors associated with these categories were assessed separately using the chi-square test as shown below.

4.10.1 Factors affecting underweight

As shown in Table 4.16, the mother's education, birth weight, pregnancy age, a child facing his/her mouth away from food during mealtime, consumption of processed food, energy intake and fat intake were significantly associated with underweight. The remaining factors were found insignificant with underweight.

The survey shows that there was a significant association of underweight with a mother's education. Children of mothers completing education only up to primary or secondary level were found to be underweight. Since the survey was carried out in an urban part of Nepal, the illiteracy rate was found to be nil. In a study where socioeconomic determinants of child nutritional status were compared between rural and urban areas, maternal education was found to be a significant determinant of child WAZ in both areas (Smith *et al.*, 2005).

The birth weight of the child was also found to be significantly associated with the prevalence of underweight. Children who were below 2.5 kg during birth were found to be underweight. A significant association between low birth weight and malnutrition has been found in several studies (Rahman *et al.*, 2016; Ntenda, 2019).

The age of the first pregnancy of the mother and underweight was found to be significantly associated with more children being underweight among mothers who were pregnant below 20 years of age. A younger pregnancy age is attributed to malnutrition by Wemakor *et al.* (2018).

The child turning his/her face or body away from food was found to be significantly associated with being underweight as feeding problems such as food refusal may harm a child's health. Children with ASD may have a higher risk of nutritional deficiency as a result of abnormal eating habits (Schreck *et al.*, 2004a). This may then result in undernutrition (Marí-Bauset *et al.*, 2015).

The consumption of processed food and underweight was also found to be significantly associated. Underweight children were found to frequently consume processed food in a given week. Over-consumption of processed foods can displace the consumption of other nutritious food which can potentially increase a child's risk of inadequate nutrient intake and contribute to undernutrition (Pries *et al.*, 2019a).

Calorie intake and fat intake were also found to be significantly associated with being underweight, with the majority of underweight children found to have calorie and fat intake below 80% of RDA. Ogechi *et al.* (2007) also found that underweight was associated with diets deficient in calories and fat.

Table 4.16 (a): Factors associated with underweight among autistic children

Factors	WAZ		χ^2 - value	P- value
	Underweight	Normal		
Mother's education				
Primary/Secondary	4	8	5.953 _f	0.038 _f
Higher Secondary	0	20		
University	1	23		
Birth weight				
Below 2.5 kg	4	15		0.035 _f
Above 2.5 kg	1	80		
Age at first pregnancy				
Below 20 years	5	35		0.009 _f
Above 20 years	0	60		
The child turns his/her face or body away from food				
Never	0	10	6.60 _f	0.040 _f
Rarely	0	20		
Seldom	0	8		
Occasionally	2	22		
Often at every meal	3	35		

The 'f' symbol denotes values of Fisher's exact test

Table 4.16 (b): Factors associated with underweight among autistic children

Factors	WAZ		χ^2 - value	P- value
	Underweight	Normal		
Processed food				
Regular	3	18	6.82 _f	0.042 _f
Frequently	2	51		
Rare	0	25		
Never	0	1		
Energy intake				
<80% of RDA	4	15		0.039 _f
80%-120% of RDA	1	36		
>120% of RDA	0	44		
Fat intake				
<80% of RDA	3	0	8.234 _f	0.032 _f
80%-120% of RDA	1	11		
>120% of RDA	1	84		

The 'f' symbol denotes values of Fisher's exact test

4.10.2 Factors affecting stunting

As shown in Table 4.17, pregnancy age, exclusive breastfeeding, processed food, calorie intake and fat intake were found to be significantly associated with stunting. The remaining factors were found insignificant with stunting.

The age of the first pregnancy and stunting were found to be significantly associated. More number of stunted children belonged to mothers who had their first pregnancy below 20 years of age. Similarly, exclusive breastfeeding was also found to be significantly associated with stunting, as more children who were not exclusively breastfed were found to be stunted. In

research carried out to determine the risk factors of stunting, non-exclusive breastfeeding and early pregnancy age were found to be significantly associated with stunting (Budiastutik and Rahfiludin, 2019).

The intake of processed food and stunting was also found to be significantly associated. The intake of processed food and beverages in a given week was found to be frequent among children who were stunted. Regular consumption of unhealthy snacks and beverages was found to be associated with inadequate nutrient intake which can contribute to poor growth outcomes (Pries *et al.*, 2019b).

Similarly, calorie and fat intake were also found to be significantly associated with stunting. In the study, more children who were stunted were found to have a calorie and fat intake below 80% of RDA. In a study carried out by (Mahfouz *et al.*, 2022), inadequate dietary fat and calorie intake were found to play a significant role in the development of stunting.

Table 4.17 (a): Factors associated with stunting among autistic children

Factors	HAZ		χ ² - value	P- value
	Stunting	Normal		
Age at first pregnancy				
Below 20 years	8	34		0.045 _f
Above 20 years	2	60		
Exclusive breastfeeding				
Yes	0.96	48.08		0.016 _f
No	8.65	42.31		
Processed food				
Regular	0.96	16.35		0.014 _f
Frequently	7.69	50.96		
Rare	0.96	23.08		
Never	0	0		

Table 4.17 (b): Factors associated with stunting among autistic children

Factors	HAZ		χ ² - value	P- value
	Stunting	Normal		
Energy intake				
<80% of RDA	6.73	15.38		0.032 _f
80%-120% of RDA	2.88	33.65		
>120% of RDA	0	41.35		
Fat intake				
<80% of RDA	5.77	0		0.029 _f
80%-120% of RDA	1.92	11.54		
>120% of RDA	1.92	78.85		

The 'f' symbol denotes values of Fisher's exact test

4.10.3 Factors affecting thinness/obesity

As shown in table 4.17, age, child closing his/her mouth tightly when food is presented, child accepting or preferring a variety of food, intake of processed food and calorie intake were found to be significantly associated with thinness/obesity. The remaining factors were found to be insignificant with thinness/obesity.

The child's age and thinness/overweight was found to be significantly associated. In the study, younger children were found to be both thin and obese. Similar results were found by (Kamal *et al.*, 2019) where younger autistic children were found to have a lower BMI for age. In another study by Hill *et al.* (2015), the prevalence of overweight and obesity was significantly higher in age groups of 2-5 years and 12-17 years. The findings of this study showed similar results in the younger age group but not in the older age group which may be due to the less number of children in the older group.

The child closing his/her mouth tightly when food is presented was found to be significantly associated with thinness/obesity. Children who were found to be thin were found to refuse food more often than children who were obese. Refusal of food by children with ASD may result in a higher risk of nutritional deficiency (Schreck *et al.*, 2004a). This may then result in

undernutrition (Marí-Bauset *et al.*, 2015). Similarly, observed less food refusal in those with higher BMI which is similar to the findings of this study.

Similarly, children accepting or preferring a variety of food and thinness/obesity were found to be significantly associated. Limited food variety in children with autism may result in a greater risk of nutritional inadequacy (Cornish, 1998; Herndon *et al.*, 2009) which can further deteriorate a child's nutritional status.

The consumption of packaged foods and beverages was also shown to be significantly associated with thinness/obesity. Frequent consumption of processed snacks and beverages can hamper the consumption of nutritious food which may further hamper a child's health and nutritional status (Pries *et al.*, 2019a). Similarly in a study conducted by Goyal *et al.* (2011), consuming junk foods and snacks was found to be a determining factor of overweight and obesity. Another study by Şengüzel *et al.* (2021) found a significant association between obesity and the consumption of packaged foods in children with autism.

There was a significant association between calorie intake and thinness/obesity with more obese children whose calorie intake was more than 120% of RDA. Padmanabhan and Shroff (2020) also found an association between total energy intake and BMI value.

Table 4.18 (a): Factors associated with thinness/obesity among autistic children

Factors	BAZ			χ^2 - value	P-value
	Thinness	Normal	Obesity		
Age					
(1-3) years of age	0.96	21.15	6.73	12.840 _f	0.043 _f
(4-6) years of age	2.88	47.12	12.5		
(7-9) years of age	1.92	1.92	0		
(10-12) years of age	0	0.96	1.92		
(13-15) years of age	0	0.96	0.96		
The child closes his/her mouth tightly when food is presented					
Never	0	20.19	7.69		0.039 _f
Rarely	0	26	7.69		
Seldom	0.96	20.19	2.88		
Occasionally	1.92	5.77	3.85		
Often at every meal	2.88	0.96	0		
The child accepts or prefers a variety of foods					
Never	2.88	3.85	0		0.025 _f
Rarely	1.92	28.85	4.81		
Seldom	0.96	15.38	9.62		
Occasionally	0	21.15	4.81		
Often at every meal	0	2.88	2.88		

Table 4.18 (b): Factors associated with thinness/obesity among autistic children

Factors	BAZ			χ^2 - value	P- value
	Thinness	Normal	Obesity		
Processed food					
Regular	1.92	10.58	4.81		0.045 _f
Frequently	2.88	42.31	14.42		
Rare	0.96	17.31	2.88		
Never	0	1.92	0		
Calorie intake					
<80% of RDA	3.85	13.46	2.88		0.028 _f
80%-120% of RDA	1.92	26.92	5.77		
>120% of RDA	0.96	31.73	23.08		

The 'f' symbol denotes values of Fisher's exact test

Part V

Conclusions and recommendations

5.1 Conclusions

The study has assessed the nutritional status of autistic children and adolescents aged 2-15 years and the results indicate that malnutrition is prevalent among autistic children with various factors acting synergistically contributing to the malnutrition problem.

The following points were concluded from the study:

1. The overall prevalence of malnutrition among the participants was 4.8% and 9.6% for moderately underweight and moderately stunting respectively. Similarly, 5.8% of autistic children were found to be moderately thin, 14.4% were found to be overweight, 5.8% were obese and 1.9% were severely obese.
2. Stunting (6.2%), underweight (9.2%), moderately thin (4.6%), overweight (13.8%) and obese (4.6%) were found to be more prevalent in (4-6) age groups as compared with other age groups. Male children were more affected by both undernutrition and overnutrition than female children.
3. The t-test analysis of the determinants of nutritional adequacy indicated that mean calorie intake was significantly higher for age groups (2-3) years and (4-6) years whereas significantly lower for (13-15) years. Similarly mean protein intake was significantly higher for age group (2-3) years (4-6) years. The mean total fat intake was found to be significantly higher in age groups 2-3) years, (4-6) years and (7-9) years. The mean iron intake was found to be significantly lower in the age group (4-6) years and (13-15) years.
4. The comparison of the dietary intake of the children under the study with RDA values by NIN revealed that the mean calorie (44.2%), protein (96.2%) and total fat (81.73%) were found to be above 120% of RDA whereas the mean calcium (45.2%) and iron (80.8%) intake was found to be below 80% of RDA.
5. The Questionnaire on Pediatric Gastrointestinal Symptoms—Rome III Version found that the most common type of functional GI disorder found was functional constipation (33.7%) followed by nonretentive faecal incontinence (7.7%) and irritable bowel syndrome 4.8%).
6. Mother's education, birth weight, age at first pregnancy, a child facing his/her mouth away from food during mealtime, consumption of processed food, energy intake and fat intake were found to be significantly associated with being underweight.

7. The age at first pregnancy, exclusive breastfeeding, processed food, calorie intake and fat intake was found to be significantly associated with stunting.
8. Child's age, child closing his/her mouth tightly when food is presented, child accepting or preferring a variety of food, intake of processed food and calorie intake were found to be significantly associated with thinness/obesity.
9. The present study points out the need of making a comprehensive, integrated and multi-sectoral plan for addressing the problem of malnutrition in autistic children.

5.2 Recommendations

For the work, it can be recommended that the nutritional status and its associated factor study can be best by taking the large sample size and large area. Based on the results of the present study following recommendations could be made to improve the nutritional status of autistic children in the survey area.

1. Surveys of this nature should be carried out at regular intervals so that they will assist the stakeholder to formulate plans and policies for the betterment of nutritional status.
2. Similar cross-sectional, descriptive or longitudinal surveys can be conducted to determine the magnitude and distribution of malnutrition and other probable causes of malnutrition in ASD children.
3. The pattern of food eating was studied but the dietary diversity score was not studied so the dietary diversity score with energy value needs to be studied in future.
4. At last, apart from anthropometric indices other indices should also be used for assessing malnutrition accurately.

Part VI

Summary

The study was conducted to assess the nutritional status, mealtime behaviour and gastrointestinal disorders of autistic children aged 2-15 years in different Autism Centers in Kathmandu Valley.

The study included 104 children and adolescents based on a purposive sampling technique. A cross-sectional descriptive survey using measurements of weight, height and 24-hour dietary recall was carried out to determine the nutritional status and a structured questionnaire was administered to the parent children to study socio-demographic conditions, mealtime behaviours and gastrointestinal disorders. The prevalence of malnutrition among survey children based on gender, age and WHO reference was studied along with mealtime behaviour and occurrence of GI disorders. Data collected was analyzed using WHO Anthro-plus and SPSS version 20.2. t-test was used to analyze the nutrient adequacy of children. The chi-square test and Fischer exact test were used to analyze the factors associated with nutritional status.

Out of 104 children, 81 boys and 23 females were taken in the study. The overall magnitudes of malnutrition among the study population were 4.8% and 9.6% for moderately underweight and moderately stunting respectively. Similarly, according to BMI for age, 5.8% of autistic children were found to be moderately thin, 14.4% were found to be overweight, 5.8% were obese and 1.9% were severely obese. More autistic children were found to have a higher BMI for their age and were overweight and obese. Males had a greater prevalence of both undernutrition and overnutrition than females. The 4-6 age group had the highest prevalence of malnutrition suggesting that pre-school autistic children are more at risk of malnutrition.

The average consumption of calories (44.2%), protein (96.2%), and total fat (81.73%) among the study participants' children were found to be above 120% of the RDA, while average intakes of calcium (45.2%) and iron (80.8%) were found to be below 80% of the RDA given by the NIN. These findings show that autistic children may be in danger of micronutrient deficiencies, such as those in calcium and iron, even when they consume an acceptable amount of calories.

Among the various GI disorders under the QPGS-RIII, functional constipation (33.7%) was the most common type of disorder followed by nonretentive faecal incontinence (7.7%) and irritable bowel syndrome (4.8%).

There was a significant association of underweight with the education of the mother, birth weight, age at first pregnancy, a child turning his/her face during mealtime, consumption of processed foods, energy intake, and fat intake ($p < 0.05$). Similarly, stunting was observed to be significantly associated with age at first pregnancy, exclusive breastfeeding, processed food, calorie and fat intake, and processed food consumption. Thinness/obesity was significantly associated with the child's age, his/her tendency to close their mouth tightly when food is provided, acceptance of or preference for a range of foods, consumption of processed foods, and calorie intake.

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Appendices

Appendix-A Consent letter

मन्जुरीनामा पत्र

नमस्कार।

म निहारिका चित्रकार, हाल पोषण तथा आहार बिज्ञान बिभाग, केन्द्रिय प्राविधि क्याम्पस धरानमा अध्यनरत छु | यस बिसय अन्तर्गत स्नातक तह पुरा गर्न यहाँ समवक्ष सर्वेक्षण तथा सोधकार्यका लागि आएको छु। मेरो सोधकार्य को बिषय “Nutritional status of children with Autism Spectrum Disorder” रहेको छ।

यस अध्यनका लागि तपाइको छोरा/छोरीलाई सहभागी गराउन म तपाइलाई यस सर्वेक्षणका केहि प्रश्नहरु गर्नेछु साथै तपाइको बच्चाको केहि नाप तौल लिनेछु। यस अध्यनका केहि प्रश्नहरु तपाइलाई नितान्त व्यक्तिगत लाग्न सक्छन तर तपाइले दिनुभएको सम्पूर्ण जानकारीहरुबाट मेरो अध्यनका लागि टेवा पुग्नुका साथ साथै यहाँका बालबालिकाको सु-स्वस्थ बिकासमा पनि मद्दत पुग्नेछ र सो जानकारीहरु एकदमै गोप्य राखिनेछ साथै तपाइले दिनुभएको सूचना तथा तथ्यांकको दुरुपयोग गरिनेछैन भन्ने जानकारी तपाइलाई गर्न चाहन्छु। यो अध्यनमा तपाइको सहभागिता स्वइच्छिक हुनेछ र यदि तपाइलाई कुनै पनि प्रश्नको उत्तर दिने इच्छा नभएमा तपाइले बिचमै छोड्न पनि सक्नुहुनेछ। तर म यो आशा गर्दछु कि तपाई यस अध्यनमा सक्रियताका साथ सहभागी भई हाम्रो सोधकार्यमा सहयोग गर्नु हुनेछ।

“यस सोधकार्यमा सहभागी हुनु भन्दा पहिले नै मलाई यस सोधकार्यको बारेमा सम्पूर्ण जानकारी गरिएको छ र म आफ्नु स्वेच्छाले यस कार्यमा सहभागी हुदै छु। मेरो इच्छा नभएमा म कुनै पनि समयमा यस सोधकार्यक लागि दिएको मंजुरिनामा फिर्ता लिन पाउनेछु भन्ने बिषयमा म जानकार छु।”

यस सोधकार्यमा सहभागी हुनुभन्दा पहिले मैले यस मन्जुरीनामा मा हस्ताक्षर गारेको हुँ।

अभिभावकको हस्ताक्षर :-

मिति:-

स्थान:-.....

माथि उल्लेखित सहभागीलाई यस अध्यनको उदेश्यका बारेमा सम्पूर्ण जानकारी गराईएको र सहभागीबाट सबै प्रश्नहरुको स्पष्ट उत्तर प्राप्त भएको जानकारी गराउदछु।

अन्वेसकको नाम :-.....

हस्ताक्षर:-.....

मिति:-.....

सम्पर्कको ठेगाना:-.....

Appendix-B Survey questionnaire

Survey title:

Date of visit:

Code no.....

Name of the child:

Date of birth:

Age:

Sex:.....

SECTION A: Socio-demographic information

1. Informant	<input type="checkbox"/> Mother/ <input type="checkbox"/> Father/ <input type="checkbox"/> Others specify
2. Head of the household	<input type="checkbox"/> Mother/ <input type="checkbox"/> Father/ <input type="checkbox"/> Others specify
3. Family size: Total number of family members	
4. Family type:	<input type="checkbox"/> Nuclear/ <input type="checkbox"/> joint
5. Ethnicity:	<input type="checkbox"/> Khas-arya <input type="checkbox"/> Janajati/ <input type="checkbox"/> others specify.....
6. Major source of income	<input type="checkbox"/> Business/Employment <input type="checkbox"/> Agriculture/ <input type="checkbox"/> Labor/ <input type="checkbox"/> Remittance/ <input type="checkbox"/> Other Specify:.....
7. Fathers education	<input type="checkbox"/> Secondary (6-10)/ <input type="checkbox"/> Higher secondary <input type="checkbox"/> University <input type="checkbox"/> None
8. Mother's education	<input type="checkbox"/> Secondary (6-10)/ <input type="checkbox"/> Higher secondary <input type="checkbox"/> University <input type="checkbox"/> None
9. Father's occupation	<input type="checkbox"/> Business/Employment <input type="checkbox"/> Agriculture/ <input type="checkbox"/> Labor/ <input type="checkbox"/> Remittance/ <input type="checkbox"/> Other Specify:.....
10. Mother's occupation	<input type="checkbox"/> Business/Employment <input type="checkbox"/> Agriculture/ <input type="checkbox"/> Labor/ <input type="checkbox"/> Remittance/ <input type="checkbox"/> Other Specify:.....
11. Annual income of the family	<input type="checkbox"/> below 20,000 <input type="checkbox"/> 20,000-30,000 <input type="checkbox"/> above 30,000
12. Who is involved in buying food and food items:	<input type="checkbox"/> Father/ <input type="checkbox"/> Mother/

SECTION B: Child description and anthropometric measurements

1. a. What is the present childbirth order?	<input type="checkbox"/> 1/ <input type="checkbox"/> 2/ <input type="checkbox"/> 3/ <input type="checkbox"/> 4/ <input type="checkbox"/> 5/ <input type="checkbox"/> 6/
b. if not first, what is the difference between an existing child and an earlier child	<input type="checkbox"/> 1yr/ <input type="checkbox"/> 2yr/ <input type="checkbox"/> 3yr/ <input type="checkbox"/> 4yr/ <input type="checkbox"/> >4yr
2. Birth weight of the child:	
3. Has the child suffered from a cough/cold in the past 7 days?	<input type="checkbox"/> Yes <input type="checkbox"/> No

4. Anthropometric measurements

Height (cm)	Weight (cm)	BMI	MUAC (cm)

SECTION C: Child caring practices

1. Did you breastfeed your child after birth? If yes, when did you initiate breastfeeding after birth?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Within 1 hr./ <input type="checkbox"/> Within 8 hr./ <input type="checkbox"/> Within 24 hr./ <input type="checkbox"/> After 24 hr.
2. When did you stop breastfeeding? At what age?	
3. Did you exclusively breastfeed or are you breastfeeding your child for the first six months? If no what is the reason you can share:	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> not sufficient milk production <input type="checkbox"/> medical complication <input type="checkbox"/> If other
4. How many times did you breastfeed your child in a day?	<input type="checkbox"/> < 8 times/ <input type="checkbox"/> 8-10 times/ <input type="checkbox"/> 11-12times or more
5. Did you continue or are you still breastfeeding your child? (if the child is >6 months) If no, when did you stop breastfeeding your child?	<input type="checkbox"/> yes <input type="checkbox"/> no Yrs.

6. Do you know how long children are recommended to be continuously breastfed? months
7. Did you feed colostrum milk (first yellow milk) to your child?	<input type="checkbox"/> yes <input type="checkbox"/> no
8. Did you introduce any kind of pre-lacteal feeds to your child? If yes, what type was given?	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> Animal milk/ <input type="checkbox"/> honey/ <input type="checkbox"/> jaggery/ <input type="checkbox"/> ghee/ <input type="checkbox"/> herbal paste/ <input type="checkbox"/> none
9. Did you ever bottle-feed your child? If yes, can you share the reason for the bottle feeding?	<input type="checkbox"/> yes <input type="checkbox"/> no
10. Do you know the preparation of litto? If yes, how?	<input type="checkbox"/> yes <input type="checkbox"/> no

Section C: Health and immunization

1. Have you gotten your child vaccinated according to schedule? If no, why did you miss it?	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> Thought it was not necessary <input type="checkbox"/> There was a shortage of vaccines in the centre <input type="checkbox"/> Child cried a lot/had a fever after getting the previous one.
2. Did your child have vitamin A and deworming tablets?	<input type="checkbox"/> yes <input type="checkbox"/> no
3. Were you vaccinated during pregnancy? If yes, which one?	<input type="checkbox"/> yes <input type="checkbox"/> no
4. How do you recognize that your child is ill?	<input type="checkbox"/> Lazy <input type="checkbox"/> Increase in body temperature <input type="checkbox"/> Irritability
5. Where do you take your child when he/she is ill?	<input type="checkbox"/> Health centre <input type="checkbox"/> Pharmacy <input type="checkbox"/> Jhakri <input type="checkbox"/> None

Section D: Maternal Characteristics

1. At what age did you get married?	
2. At what age did you get first pregnant?	
3. Did you have iron/folate tablets during pregnancy? If yes, when did you start to take them?	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> 1 st trimester/ <input type="checkbox"/> 2 nd trimester/ <input type="checkbox"/> 3 rd trimester
4. From where did you receive the iron/folate tablets?	<input type="checkbox"/> Health post/ <input type="checkbox"/> hospital/ <input type="checkbox"/> yourself
5. Do you know what malnutrition is? If yes, how does it happen?	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> Less food intake/ <input type="checkbox"/> curse of god/ <input type="checkbox"/> due to witch / <input type="checkbox"/> other/ <input type="checkbox"/> don't know
6. What amount of food did you eat during pregnancy?	<input type="checkbox"/> More than usual/ <input type="checkbox"/> less than usual/ <input type="checkbox"/> as usual
7. How many times per day did you eat?	<input type="checkbox"/> < 3time / <input type="checkbox"/> 3-4 times/ <input type="checkbox"/> > 4 times
8. What salt is used in your home?	<input type="checkbox"/> Iodized salt/ <input type="checkbox"/> Normal salt/ <input type="checkbox"/> <i>Dhikke</i>

Section E: BAMBI questionnaire

Think about mealtimes with your child over the past 3 months. Rate the following items according to how often each occurs, using the following scale: Never/Rarely/ Seldom/ occasionally/ Often at Almost Every Meal 1 2 3 4 5

Circle YES if you think an item is a problem for you or NO if you think it is not a problem.

1. My child cries or screams during mealtimes.	1 2 3 4 5 YES/NO
2. My child turns his/her face or body away from food.	1 2 3 4 5 YES/NO
3. My child remains seated at the table until the meal is finished.	1 2 3 4 5 YES NO
4. My child expels (spits out) food that he/she has eaten.	1 2 3 4 5 YES/NO
5. My child is aggressive during mealtimes (hitting, kicking, scratching others)	1 2 3 4 5 YES/NO
6. My child displays self-injurious behaviour during mealtimes (hitting self, biting self).	1 2 3 4 5 YES/NO

7. My child is disruptive during mealtimes (pushing/throwing utensils, food).	1	2	3	4	5
	YES/NO				
8. My child closes his/her mouth tightly when food is presented.	1	2	3	4	5
	YES/NO				
9. My child is flexible about mealtime routines (e.g., times for meals, seating arrangements, place settings).	1	2	3	4	5
	YES/NO				
10. My child is willing to try new foods.	1	2	3	4	5
	YES/NO				
11. My child dislikes certain foods and won't eat them.	1	2	3	4	5
	YES/NO				
12. My child refuses to eat foods that require a lot of chewing (e.g., eats only soft or pureed foods).	1	2	3	4	5
	YES/NO				
13. My child prefers the same foods at each meal.	1	2	3	4	5
	YES/NO				
14. My child prefers "crunchy" foods (e.g., snacks, crackers).	1	2	3	4	5
	YES/NO				
15. My child accepts or prefers a variety of foods.	1	2	3	4	5
	YES/NO				
16. My child prefers to have food served in a particular way.	1	2	3	4	5
	YES/NO				
17. My child prefers only sweet foods (e.g., candy, sugary cereals).	1	2	3	4	5
	YES/NO				
18. My child prefers food prepared in a particular way (e.g., eats mostly fried foods, cold cereals, and raw vegetables).	1	2	3	4	5
	YES/NO				

Section F: Gastrointestinal problems questionnaire

Section F1: Questionnaire on Pediatric Gastrointestinal Symptoms, Rome III Version (OPGS-RIII)

This questionnaire is about your child's digestive system (oesophagus, stomach, small intestine, and colon) and problems you can have with it. Certain problems may apply to your child and others will not.

Please try to answer all of the questions as best as you can. If it is impossible for you to answer a particular question, please answer "I don't know" where indicated.

Section F1 A: Pain and Uncomfortable Feelings in the Upper Abdomen above the Belly Button

The questions in this section are about pain and uncomfortable feelings ABOVE the belly button that your child may have had in the last 3 months.

1. In the last 2 months, how often did your child have pain or an uncomfortable feeling in the upper abdomen above the belly button?		<input type="checkbox"/> never <input type="checkbox"/> 1 to 3 times a month <input type="checkbox"/> once a week <input type="checkbox"/> several times a week <input type="checkbox"/> every day				
<i>If your child has not had ANY pain or uncomfortable feelings above the belly button in the past <input type="checkbox"/> months, please go to Section B.</i>						
2. Which of the following feelings did your child have above the belly button? (You may check one or more than one.)	a. Pain	<input type="checkbox"/> <input type="checkbox"/> no <input type="checkbox"/> yes				
	b. Nausea	<input type="checkbox"/> <input type="checkbox"/> no <input type="checkbox"/> yes				
	c. Bloating	<input type="checkbox"/> <input type="checkbox"/> no <input type="checkbox"/> yes				
	d. Feeling of fullness	<input type="checkbox"/> <input type="checkbox"/> no <input type="checkbox"/> yes				
	e. Not being hungry after eating very	<input type="checkbox"/> <input type="checkbox"/> no <input type="checkbox"/> yes				
3. In the last 3 months, how much did your child hurt or feel uncomfortable above the belly button?		<input type="checkbox"/> A little <input type="checkbox"/> Some (between a little and a lot) <input type="checkbox"/> A lot <input type="checkbox"/> A very lot <input type="checkbox"/> I don't know				
4. When your child hurt or felt uncomfortable above the belly button, for how long did it last?		<input type="checkbox"/> Less than an hour <input type="checkbox"/> 1 to 2 hours <input type="checkbox"/> 3 to 4 hours <input type="checkbox"/> Most of the day <input type="checkbox"/> All the time				
5. For how long has your child had pain or an uncomfortable feeling above the belly button?		<input type="checkbox"/> month or less <input type="checkbox"/> 2 months <input type="checkbox"/> 3 months <input type="checkbox"/> 4 to 11 months <input type="checkbox"/> year or longer				
Circle a number for your answer to each question below. In the last 2 months, when your child hurt or felt uncomfortable above the belly button, how often	0% of the time Never	25% of the time Once in a week	50% of the time Sometimes	75% of the time Most of the time	100% of the time Always	I don't know (tick)

6. Did the hurt or uncomfortable feeling get better after your child had a poop?	0	1	2	3	4	
7. Were your child's poop softer and more mushy or watery than usual?	0	1	2	3	4	
8. Were your child's poop harder or lumpier than usual?	0	1	2	3	4	
9. Did your child have more poops than usual?	0	1	2	3	4	
10. Did your child have fewer poops than usual?	0	1	2	3	4	
11. Did your child feel bloated in the belly?	0	1	2	3	4	
12. Did your child have a headache?	0	1	2	3	4	
13. Did your child have difficulty sleeping?	0	1	2	3	4	
14. Did your child have pain in the arms, legs, or back?	0	1	2	3	4	
15. Did your child feel faint or dizzy?	0	1	2	3	4	
16. Did your child miss school or stop activities?	0	1	2	3	4	

Section F1 B: Belly Aches and Abdominal Pain Around and Below the Belly Button

1. In the last 2 months, how often did your child have a belly ache or pain in the area around or below the belly button?	<input type="checkbox"/> never <input type="checkbox"/> 1 to 3 times a month <input type="checkbox"/> once a week <input type="checkbox"/> several times a week <input type="checkbox"/> every day
<i>If your child has not had ANY pain or uncomfortable feelings above the belly button in the past <input type="checkbox"/> months, please go to Section C.</i>	
2. In the last 2 months, how much did your child usually hurt in the area around or below the belly button?	<input type="checkbox"/> a little <input type="checkbox"/> some (between little and a lot) <input type="checkbox"/> a lot <input type="checkbox"/> a very lot <input type="checkbox"/> I don't know

3. When your child hurt or felt uncomfortable around or below the belly button, for how long did it last?		<input type="checkbox"/> Less than an hour <input type="checkbox"/> 1 to 2 hours <input type="checkbox"/> 3 to 4 hours <input type="checkbox"/> Most of the day <input type="checkbox"/> All the time				
4. For how long has your child had belly aches or pain around or below belly button?		<input type="checkbox"/> month or less <input type="checkbox"/> 2 months <input type="checkbox"/> 3 months <input type="checkbox"/> 4 to 11 months <input type="checkbox"/> year or longer				
Circle a number for your answer to each question below. In the last 2 months, when your child hurt or felt uncomfortable above the belly button, how often	0% of the time Never	25% of the time Once in a week	50% of the time Sometimes	75% of the time Most of the time	100% of the time Always	I don't know (tick)
5. Did it get better after having a poop?	0	1	2	3	4	
6. Were your child's poop softer and more mushy or watery than usual?	0	1	2	3	4	
7. Were your child's poop harder or lumpier than usual?	0	1	2	3	4	
8. Did your child have more poops than usual?	0	1	2	3	4	
9. Did your child have fewer poops than usual?	0	1	2	3	4	
10. Did your child feel bloated in the belly?	0	1	2	3	4	
11. Did your child have a headache?	0	1	2	3	4	
12. Did your child have difficulty sleeping?	0	1	2	3	4	
13. Did your child have pain in the arms, legs, or back?	0	1	2	3	4	
14. Did your child feel faint or dizzy?	0	1	2	3	4	
15. Did your child miss school or stop activities?	0	1	2	3	4	

Section F1 C: Bowel Movements (“Poop,” “Stool,” “Number 2”)

1. In the 2 months, how often did your child usually poop?	<input type="checkbox"/> 2 times a week or less often <input type="checkbox"/> 3 to 6 times a week <input type="checkbox"/> Once a day <input type="checkbox"/> 2 to 3 times a day <input type="checkbox"/> More than 3 times a day <input type="checkbox"/> I don't know					
2. In the last 2 months, what was your child's poop usually like? If your child poop were usually hard, for how long have they been hard?	<input type="checkbox"/> Very hard <input type="checkbox"/> Hard <input type="checkbox"/> Not too hard and not too soft <input type="checkbox"/> Very soft or mushy <input type="checkbox"/> Watery <input type="checkbox"/> It depends (his/her poops are not always the same) <input type="checkbox"/> <input type="checkbox"/> I don't know <input type="checkbox"/> Less than 1 month <input type="checkbox"/> 1 month <input type="checkbox"/> 2 months <input type="checkbox"/> 3 or more months					
3. In the last 2 months, did it hurt when your child had a poop?	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> I don't know					
Circle a number for your answer to each question below. In the last 2 months, how often	0% of the time Never	25% of the time Once in a while	50% of the time Sometimes	75% of the time Most of the time	100% of the time Always	I don't know (tick box)
4. Did your child have to rush to the bathroom to poop?	0	1	2	3	4	
5. Did your child have to strain (push hard) to make a poop come out?	0	1	2	3	4	
6. Did your child pass mucus or phlegm (while yellowish, stringy, or slimy material) during a poop?	0	1	2	3	4	
7. Did your child have a feeling of not finished after a poop (like there was more that wouldn't come out)?	0	1	2	3	4	
8. In the last <input type="checkbox"/> months, did your child have a poop that was so big that it clogged the toilet?	<input type="checkbox"/> No <input type="checkbox"/> Yes					
9. Some children hold in their poop even when there is a toilet available. They may	<input type="checkbox"/> Never <input type="checkbox"/> 1 to 3 times a month <input type="checkbox"/> Once a week <input type="checkbox"/> Several times a week <input type="checkbox"/> Every day					

do this by stiffening their bodies or crossing their legs. In the last <input type="checkbox"/> months, while at home, how often did your child try to hold in a poop?	
10. Did a doctor or nurse ever examine your child and say that your child had a huge poop inside?	<input type="checkbox"/> No <input type="checkbox"/> Yes
11. In the last <input type="checkbox"/> months, how often was your child's underwear stained or soiled with poop?	<input type="checkbox"/> Never. <i>If never, please go to Section D.</i> <input type="checkbox"/> Less than once a month <input type="checkbox"/> 1 to 3 times a month <input type="checkbox"/> Once a week <input type="checkbox"/> Several times a week <input type="checkbox"/> Every day
11a. When your child stained or soiled underwear, how much was it stained or soiled?	<input type="checkbox"/> Underwear was stained (no poop) <input type="checkbox"/> Small amount of poop in underwear (less than a whole poop) <input type="checkbox"/> Large amount of poop in underwear (a whole poop)
11b. For how long has your child stained or soiled underwear?	<input type="checkbox"/> month or less <input type="checkbox"/> 2 months <input type="checkbox"/> 3 months <input type="checkbox"/> 4 to 11 months <input type="checkbox"/> 1 year or longer

Section F1 D: Other Symptoms

Circle a number for your answer to each question below. In the last 2 months, when your child hurt or felt uncomfortable above the belly button, how often	0% of the time Never	25% of the time Once in a week	50% of the time Sometimes	75% of the time Most of the time	100% of the time Always	I don't know (tick)
1. Burp (belch) again and again without wanting to?						
2. Pass a lot of gas very frequently?						
3. Develop a clearly swollen belly during the day (you could see it swollen)?						
4. Swallow or gulp extra air (you might clear a clicking noise when your child swallow.)						

<p>5. IN THE PAST YEAR, how many times did your child vomit (throw up) again and again without stopping for 2 hours or longer?</p> <p>5a. For how long has your child had episodes of vomiting again and again without stopping?</p> <p>5b. Did your child usually feel nausea when he or she vomited again and again without stopping?</p> <p>5c. Was your child in good health for several weeks or longer between the episodes of vomiting again and again?</p>	<p><input type="checkbox"/> <input type="checkbox"/> Never. <i>If never, please go to Section E.</i></p> <p><input type="checkbox"/> Once <input type="checkbox"/> 2 times <input type="checkbox"/> 3 times <input type="checkbox"/> 4 or more times</p> <p><input type="checkbox"/> 1 month or less <input type="checkbox"/> 2 months <input type="checkbox"/> 3 months</p> <p><input type="checkbox"/> 4 to 11 months <input type="checkbox"/> 1 year or longer</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p>
<p>6. In the past <input type="checkbox"/> months, how often did food come back up into your child's mouth after eating?</p> <p>6a. Does this usually happen less than an hour after your child eats?</p> <p>6b. Does food come back up into your child's mouth while your child is sleeping?</p> <p>6c. Does your child usually feel nausea and vomit when food comes back up into his or her mouth?</p> <p>6d. Does it usually hurt your child when the food comes back up into his or her mouth?</p> <p>6e. What does your child usually do with the food that comes back up into his or her mouth?</p>	<p><input type="checkbox"/> Never. <i>If never, please go to Section E.</i></p> <p><input type="checkbox"/> 1 to 3 times a month <input type="checkbox"/> Once a week</p> <p><input type="checkbox"/> Several times a week <input type="checkbox"/> Every day</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Swallow it. <input type="checkbox"/> Spit it out.</p>

Section G: Dietary intake

a. Food frequency table:

Type of food	Frequent (at least once a day)	Regular (3\4 times a week)	Rare (once in a week or less)	Never
1. Cereals				
Rice\brown rice				
Wheat				
Maize/millet/barley				
2. Pulses/Legumes				
Whole daal				
Grams/beans/peas				
3. GLV				
4. Other vegetables				
5. Roots and tubers				
6. Fruits				
7. Dairy Products				
Milk				
Curd				
Ghee/Butter				
Paneer/cheese				

8. Meat				
White meat (chicken/fish)				
Red meat (mutton/beef/pork)				
Egg				
9. Processed, packaged foods/fast food				

b. 24-hour dietary recall

Timing	Time	Description of food	Brand (if possible)	Quantity/Serving size
Breakfast				
Lunch				
Snacks				
Dinner				