INVESTIGATING NUMBER OF CHILDREN WITH DISABILITIES IN HUSM REGISTRY AND LEVEL OF PARTICIPATION IN PHYSICAL ACTIVITIES: A PILOT STUDY

By

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CERTIFICATE

This is to certify that the dissertation entitled

INVESTIGATING NUMBER OF CHILDREN WITH DISABILITIES IN HUSM REGISTRY AND LEVEL OF PARTICIPATION IN PHYSICAL ACTIVITIES: A PILOT STUDY

Is the bona fide record of research work done by

RAFIDAH BINTI BAKRI

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under my supervision

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CONTENTS

CHAPTER 3: RESEARCH METHODOLOGY

CHAPTER 4: RESULT

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

HUSM	Hospital Universiti Sains Malaysia
WHO	World Health Organization
JKM	Jabatan Kebajikan Masyarakat (Social Welfare Department)
ICD	International Statistical Classification of Diseases and Related Health Problems
PAQ-C	Physical Activities Questionnaire for Children

List of Appendices

ABSTRACT

Currently, number of children with disabilities in Malaysia was only based on estimation by World Health Organization (WHO). Besides, they are more likely to be sedentary, placing them at higher risk of associated health condition than normal children. The purpose of this study was to investigate the number of children with disabilities in the Hospital USM registry throughout 2011 and levels of participation of children with physical disabilities in physical activities. Number of children with disabilities was obtained by accessing the HUSM registry system and were categorized according to the International Statistical Classification of Diseases and Related Health Problems (ICD-10). Subsequently, 35 respondents with physical disabilities were randomly selected to investigate their level of participations in physical activities.Data for physical activities was collected using translated version of Physical Activity Questionnaire for Children (PAQ-C) and analyzed using the SPSS 20.0 software. Descriptive analysis was performed to investigate the number of children with disabilities in the Hospital USM registry. Independent T-Test was performed to analyze mean difference of the physical activity score between genders as well as between those who attend rehabilitation intervention and not attend. One-way ANOVA was performed to analyze mean difference of physical activity score between family incomes as well as between types of disabilities. Present study found that there were a total of 898 children with disabilities that have been admitted into the Hospital USM from 1st January until 31st December 2011 and 1121 infants categorized as high risk baby. All 35 respondents in this study had low mean physical activity score. This indicated that participation of children with physical disabilities in

physical activities was generally low. The test result also revealed that there is no significant difference of level of participation in physical activities between gender, rehabilitation services, as well as family income (p>0.05). But there is significant difference in level of participation in physical activities between type of disabilities (p=0.003).

ABSTRAK

Jumlah kanak-kanak kurang upaya di Malaysia hanyalah berdasarkan anggaran daripada Persatuan Kesihatan Sedunia (WHO) sahaja. Di samping itu, mereka lebih cenderung untuk menjadi tidak aktif dan meletakkan mereka pada risiko yang lebih tinggi terhadap masalah kesihatan berbanding kanak-kanak normal. Justeru, kajian ini dijalankan untuk mengkaji jumlah kanak-kanak kurang upaya di dalam sistem pendaftaran Hospital USM sepanjang tahun 2011 serta tahan penglibatan mereka dalam aktiviti fizikal. Jumlah kanak-kanak kurang upaya diperoleh dengan mengakses sistem pendaftaran Hospital USM menngunakan kod daripada *International Statistical Classification of Diseases and Related Health Problems* (ICD-10). Kemudian, 35 responden yang mempunyai masalah kurang upaya fizikal telah dipilih secara rawak untuk mengenalpasti tahap penglibatan mereka dalam aktiviti fizikal. Data diperoleh dengan menggunakan Borang Soal Selidik Kanak-Kanak (PAQ-C) yang telah diterjemah ke dalam bahasa Melayu dan dianalisa dengan menggunakan perisisan SPSS versi 20.0. Analisis deskriptif telah dijalankan bagi mengkaji jumlah kanak-kanak kurang upaya di dalam sistem pendaftaran Hospital USM. Ujian T untuk sampel-sampel bebas telah digunakan untuk mengkaji perbezaan antara min markah aktiviti fizikal dan jantina serta perkhidmatan pemulihan. Ujian ANOVA sehala telah dilajankan untuk mengkaji perbezaan min antara pendapatan keluarga, jenis kurang upaya dan tahap penglibatan mereka dalam aktiviti fizikal. Kajian ini mendapati terdapat 898 orang kanak-kanak kurang upaya di dalam sistem pendaftaran Hospital USM sepanjang tahun 2011 dan 1121 bayi yang dikategorikan sebagai bayi berisiko tinggi. Keputusan ujian menunjukkan tidak terdapat perbezaan yang ketara antara jantina, perkhidmatan pemulihan,

pendapatan keluarga dan tahap penglibatan dalam aktiviti fizikal. ($p>0.05$) Tetapi terdapat perbezaan yang ketara antara jenis kurang upaya dan tahap penglibatan mereka dalam aktiviti fizikal ($p=0.003$)

CHAPTER 1

INTRODUCTION

1.1 Study background

The World Health Organization (WHO) defines children with disabilities as any children who are unable to ensure himself, wholly or partly, the necessities of a normal individual and or social life, as a result of a deficiency either congenital or acquired, in his physical or mental capabilities (WHO, 1998). According to the Malaysian Person with Disability Act 2008, children with disabilities is referring to children who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society. Department of Social welfare classifies disabilities into hearing, vision, physical, speech/language, learning and mental disabilities.

International Classification of Functioning, Disability and Health (ICF) define participation as involvement in a life situation (WHO 2001). For children and youth, involvement in life situations includes participation in recreational and leisure activities as well as school and work activities. Recreational and leisure activities include active physical activities, sports, play, social, artistic, creative, cultural, and skill-based activities (King *et al.*, 2003). The ICF provides a new perspective in viewing disabilities. It recognizes that disability is a universal human experience and its shifts the focus from the cause of a specific disability to the impact it has on the person's lives in the society. The ICF takes into account the social model of disability, which regards disability as a social issue and not an individual's attribute.

1.2 Objectives of the Study

1.2.1 General Objectives

1. To investigate number of children with disabilities in the HUSM registry, registered from 1st Jan 2011 – 31st Dec 2011.
2. To investigate the levels of participation of children with physical disabilities that has been identified from objective 1 in their physical activities.

1.2.2 Specifics Objectives

1. To find the age distribution of children with disabilities in HUSM registry.
2. To find the distribution of case of disable condition in HUSM registry.
3. To find the number of high risk infant in HUSM registry.
4. To determine the difference in the level of participation in physical activities between boys and girl with physical disabilities that has been identified from objective 1.
5. To determine the difference in the level of participation in physical activities between children with physical disabilities that has been identified from objective 1 that receives rehabilitation services and those who do not receive rehabilitation services.
6. To determine the difference in the level of participation in physical activities between family with higher income and lower income.
7. To determine the difference in the level of participation in physical activities between different types of disabilities of children with physical disabilities that has been identified from objective 1.

1.3 Significance of the Study

The procedure used in this pilot study may be applied to investigate number of children with disabilities in other hospital registry in order to investigate the prevalence of children with disabilities in the whole country. The procedure may also be used to investigate other types of disabilities. It is an important public health issue to estimate the required data on prevalence of people with disabilities accurately to help the government to construct service plans more accurately. Furthermore, this research may produce a new knowledge on levels of participation of children with physical disabilities in physical activities. It was well reported that children with physical disabilities are less active, yet no investigation has been done to investigate their levels of participation in Malaysian population.

CHAPTER 2

LITERATURE REVIEW

2.1 Prevalence of Children with Disabilities in Other Countries

WHO stated that 10% of the population in any country in the world has some form of disability. It was estimated that among the 10% of the population with disability, one third of them are children less than 15 years old (WHO, 1998). Translating the figure into Malaysian population of 28 million, there are about one million children less than 15 years old with some form of disability that requires special care in Malaysia.

In Minnesota, USA, Elizabeth Lightfoot *et al.* (2011) used a statewide electronic system (administrative data) for collecting child welfare data in 2000 called the Social Service Information System (SSIS) to explore the prevalence and characteristics of children with disabilities within the child welfare system. Analysis of the cleaned SSIS data found that 22% of the 6270 children ages 0–18 with substantiated maltreatment had a reported disability diagnosis code. Among the 3982 children over the age of 5 with substantiated maltreatment, 27.9% had a reported disability diagnosis code.

Another study in the US utilized Clinical Risk Groups (CRGs), which is administrative data system to classify children 0–18 years, in a mid-sized health plan into mutually exclusive categories and severity groups to identify and categorize children with chronic health conditions (King *et al.*, 2003) . Compared to national prevalence norms for selected conditions, CRGs do well in identifying patients who have conditions that require interaction with the health care system.

Meanwhile in Australia, the main data source for estimating the prevalence of disability is the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC), conducted in 1981, 1988, 1993 and 1998. Data are gathered from both households and cared accommodation. In 1998, 594,000 children aged 0–14 years were reported as having a health condition, of which 296,400 reported impairments of body functions and/or structures, 245,200 reported activity limitations and 188,700 reported participation restrictions (Australian Bureau of Statistics, 1998).

In Taiwan, Der-Chung Lai *et al.* (2012) used annual data released from Department of Statistics of Taiwan Ministry of the Interior publishes Statistical Yearbook of Interior and the information includes the numbers of cases by age. To calculate the prevalence, they obtained data on the numbers of boys, girls, and total population in each age group in each area from the Monthly Bulletin of Interior Statistics. They found that from 2004 to 2010, the registered cases between 3 and 17 years old ranged from 20,531 to 23,547, and the prevalence of intellectual disability increased constantly from 4.40/1000 to 5.79/1000.

2.2 Case-Finding Method of Prevalence

There are two main ways to investigate the prevalence of children with disabilities. First is an 'administrative prevalence,' which the prevalence was to obtained from the number of all persons receiving or qualifying for the services offered by agencies, such as Welfare Department (JKM) in Malaysia. It generally observes lower prevalence rates because it tends to identify only persons who received services but overlooks those who are not (Larson *et al.*, 2001). Second method is a 'population-based survey,' which screens a representative sample of the population either through interviews or diagnostic

examinations. The results can be generalized to the whole target population. However, this method tends to observe higher prevalence because the case ascertainment is more likely to be complete (Der-Chung Lai, 2012).

Investigating prevalence through population based survey has more advantages compared to administrative data collections. Administrative data collections have several limitations in terms of establishing trends over time. Firstly, administrative data sources provide an indication of changes over time in the level of service provision to children with disabilities, rather than changes in the underlying prevalence of childhood disability. Second, administrative data relating to income support or disability support services include information about a sub-set of people with disability, namely those who are eligible for benefits or services, and such eligibility criteria may change over time (AIWH, 2004).

2.3 Current Status in Malaysia

In Malaysia, the actual number of children with disability locally is not available. The most frequent method used to provide the prevalence was by estimation. So far, the number of children with disabilities can only be estimated grossly. Local experience has shown that a significant majority of children referred to the Welfare Department do not get on the national register and an even larger number go undetected (Amar-Singh, 2008). Ministry of Health Malaysia (MOH) provides a public care service include care of children with special needs (CWSN) at health clinic and community level. MOH data reported only 2,881 new children aged 0-12 years with disability in 2005 that were registered. In 2007, a total of 1,384 new cases were detected among children of 0-12 years. In 2009, a total of 1,470 new cases of disabilities were detected among children 0-18 years, an increase of 2% compared

to 2008, which were 1,442 cases (MOH, 2008). However, total number of children with disabilities is unknown. This is because there is no statistical report that reveals the total number of children with disabilities.

A child with disabilities is a group of children that require special health care needs and services. Identifying children with special health care needs (CSHCN) is an essential first step in order to assess and plan for appropriate programs and services for them. Having an accurate data on prevalence of children with disabilities is important for service provision planning. The data may enable the government to provide adequate financial budget to support the service provision to improved health and quality of life for children with disabilities. The data may also assist the government to plan for educational and rehabilitation program for children with disabilities.

2.4 Activities Participation

In the ICF, problems with human functioning are categorized in three inter-connected areas which are impairment, activity limitations and participation restriction. Impairment refers to problems in body function or alterations in body structure such as paralysis or blindness. Activity limitations are difficulties in executing activities such as walking or eating as a result from the impairment. Third area which is participation restrictions are problems is defined as limitation to participate or involve in any area of life such as in ability to work or to participate in sports (WHO 2011). Participation is a complex phenomenon so it is important to understand more clearly how personal, environmental, and family factors influence the child's involvement in daily activities.

2.5 Importance of Participation in Physical Activities for Children with Physical Disabilities

Leisure activities for children are regarded as the time designated for freely chosen activities, performed when not involved in self-care or work or school. Specifically, a leisure activity is defined as everyday activities of childhood in all sport, entertainment, learning and religious expression (King *et al.,* 2003; Majnemer, 2009). Promoting moderate levels of physical activity among children with disabilities is an important goal for public health and public policy, as regular physical activity improves well-being and contributes to the prevention or delay of chronic disease (Rimmer *et al.,* 2004). It is important to encourage physical activities among children with disabilities. This is because the physical activities has therapeutic value which may reverse deconditioning secondary to impaired mobility, may optimize physical functioning, and enhance overall well-being (Durstine *et al.*, 2000).

Physical activities may also improve the inclusion and well-being of children with disabilities in at least two ways. Firstly, it may change how the community views and feels about children with disabilities. Secondly, it may improve the psychological wellbeing of the children. Dykens *et al.* (1998) reported that physical activities could enhance psychological wellbeing of children with disabilities through the opportunities to form friendships, express creativity and develop a self-identity. Furthermore, providing opportunities for children to be active and opportunity to choose activities freely are essential for the development of skill competencies, socializing with peers, exploring personal interests and enjoying life

2.6 Level of Participation in Physical Activities among Children with Disabilities

However, Brown and Gordon (1987) reported that children with disabilities are more likely to be sedentary than other children, placing them at higher risk of obesity and associated health conditions. Compared to children without disabilities, children with disabilities tend to engage in fewer recreational and social activities. Their daily life had less variety and in slower tempo, with more time being spent in dependent activities, quiet recreation, and personal care. They also have less participation in social engagements, active recreation, household tasks and activities away from home (Brown & Gordon, 1987). The participation of children and youth with disabilities decreases as they grow up. As a result in adulthood, their participation is limited. The prevalence of childhood disability and limitations to participation in daily activities to be 6.5% in the USA (Newacheck and Halfon 1998), 4.2% in the most recent Canadian survey (Statistics Canada 2002), and 4.6% in Australia (Bradbury et al. 2001).

Studies also reported that children and youth with physical disabilities participate less in leisure activities than their able bodied peers (Bult *et al.,* 2010). An estimated 3.6% of children with chronic physical health conditions have activity limitations that restricted their participation (McDougall *et al.,* 2004), including participation in formal and informal leisure and recreation activities outside of school. As a result they may less likely to derive the benefits associated with participation (Parkinson, 2007).

The literature review highlighted the need for an accurate data of prevalence of children with disabilities. The big different between the WHO estimate prevalence of children with disabilities and those who are registered, underscore the needs for a method

to collect a more accurate prevalence of children with disabilities. Therefore, this pilot study is going to investigate number of children with disabilities from a hospital registry.

Secondly, the literature review has also highlighted the importance of activities participation for children with disabilities. Hence, the second objective of this study is to investigate the status of activity participation among children with physical disabilities.

Thus, the purpose of this study is to investigate number of children with disabilities in registry system from 1st January until 31st December 2011 in HUSM, based on their condition of disabilities as well as to investigate level of participation of children with physical disabilities in physical activities.

CHAPTER 3

METHODOLOGY

This research involved 2 phases. Phase 1 is to obtain the number of children with disabilities in HUSM registry and phase 2 is to investigate their level of participation of children with physical disabilities in physical activities.

3.1 Subjects

The sample size and number of children with physical disabilities involved to achieve the second objectives was determined based on the result obtained in the phase 1. We included 35 children with physical disabilities age from 13-17 years. This age range is selected because it is a school age, thus their participation in exercise and sports are more structured. It is also widely accepted that only children aged more than 10 years can reliably and accurately self-report their physical activity behavior (Siesmaa *et al*, 2010)

3.2 Inclusion criteria

- Children age from 13-17 years old
- Children with physical disabilities.

3.3 Exclusion criteria

- Having any form of intellectual disabilities
- Suffering multiple disabilities

3.4 Instrument

The investigation of number of children with disabilities in this pilot study is based on International Statistical Classification of Diseases and Related Health Problems (ICD-10). ICD-10 is the standard diagnostic tool for epidemiology, health management and clinical purposes. It is used to monitor the incidence and prevalence of diseases and other health problems. ICD-10 coding which is related to children with disabilities (APPENDIX E) was entered into both registry systems, to search for children according to coding.

Translated Physical Activities Questionnaire for Children (PAQ-C) (Kowalski K.C. *et al*, 2004) was used to measure level of participation in physical activities. PAQ-C is a self-administered, 7-day recall instrument to assess general levels of physical activity. The questionnaire is in English language, thus require translation to be used in local population. The questionnaire was translated and small modification was made in order to suit children with physical disabilities in Malaysian culture as well as to achieve the study objectives. Prior to the investigation, the translated PAQ-C (APPENDIX F) was sent for an expert panel review and to a language expert to check for their language and validity.

3.5 Procedure

3.5.1 Investigation of number of children with disabilities

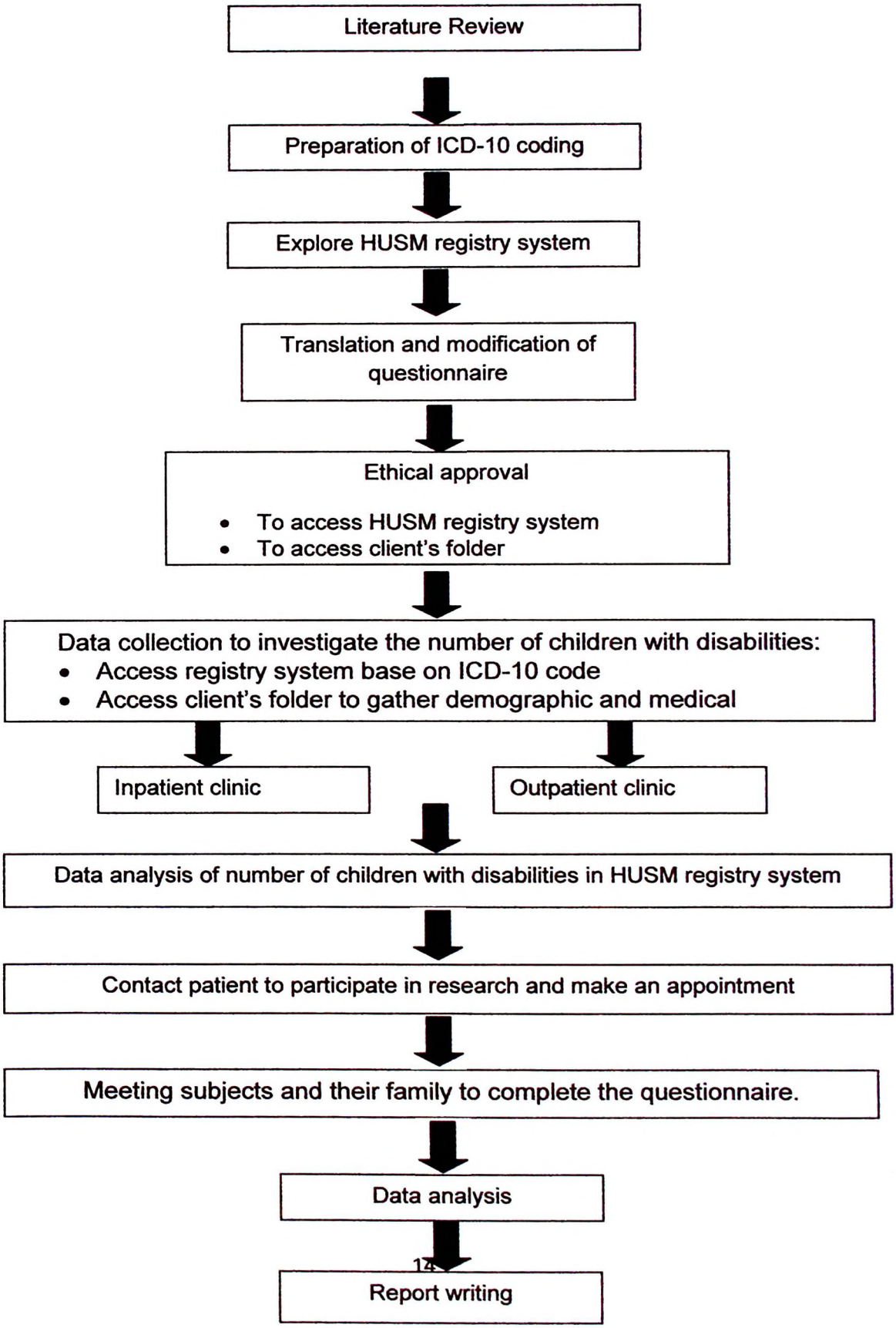
Number of children with disabilities was obtained by accessing the HUSM registry system. There are 2 parts of registry system in HUSM, which are inpatient registry and outpatient clinic registry. A list of children was obtained and listed according to coding. Children who age from 0 to 18 years old, were identified and their folder were accessed to obtain their demographic and medical information. Data gathered from inpatient clinic and

outpatient clinic were combined to obtain the number of children with disabilities in HUSM. The results were sorted and tabulated using descriptive analysis to determine the number of children with disabilities in HUSM according to condition and type of disabilities. From this phase, it is expected that the exact number of children with disabilities in HUSM registry system from 1st January 2011 to 31st December 2011 could be determined. The number of children with disabilities were categorized and arranged according to ICD-10.

3.5.2 Investigation of level participations of children with physical disabilities in physical activities

Parent or guardian of potential subjects identified from the phase 1 were contacted via phone and invited to participate in the investigation. An appointment was made for the data collection at the Exercise and Sport Science Lab, PPSK. The PAQ-C and consent form were given to the subjects' parents or guardian. The subjects and their parents or guardian were asked to complete the questionnaire.

3.6 Flow Chart of Data Collection



3.7 Statistical analysis

All data has been analyzed by Statistical Package for Social Sciences (SPSS) software Version 20.0. Descriptive analysis was used to obtain number of children with disabilities in HUSM registry. Independent T-Test was performed to analyze mean difference of physical activity score between genders as well as between rehabilitation services. One-way ANOVA was performed to analyze mean difference of physical activity score between family incomes as well as between types of disabilities. Statistical significance was accepted at $p<0.05$. All the data were expressed as mean and standard deviation (SD).

CHAPTER 4

RESULT

4.1 Number of Children with Disabilities in Hospital USM Registry System

4.1.1 Age distribution

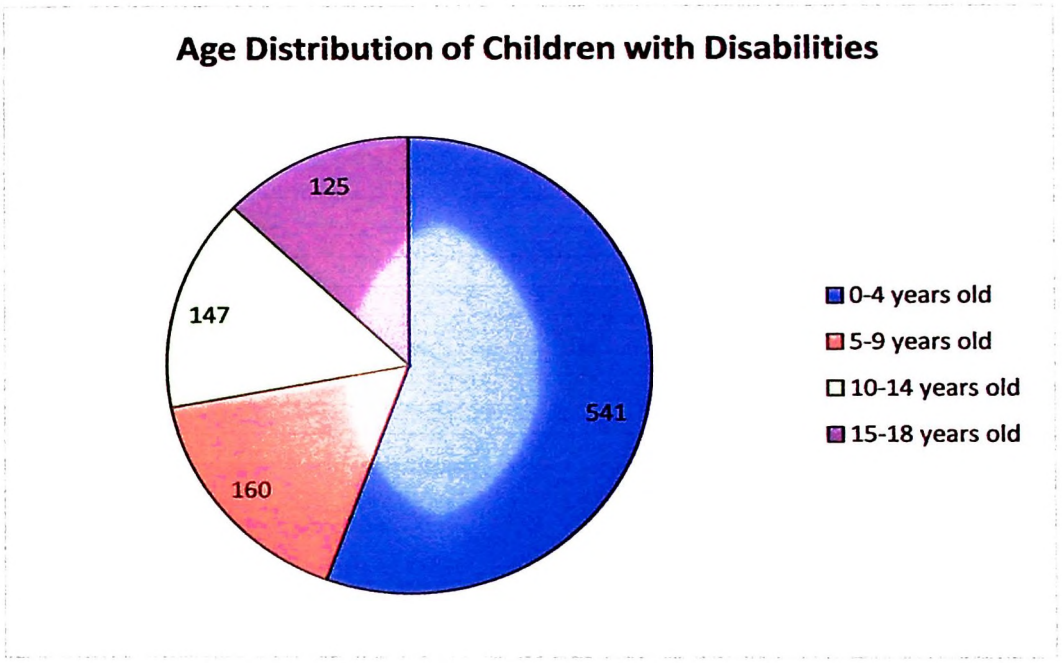


Figure 4.1 Age distribution of children with disabilities in Hospital USM registry

There were a total of 898 children with disabilities that have been admitted into the Hospital USM ward from 1st January until 31st December 2011 of which more than half 541 age from 0 to 4 years old. Detail age distribution illustrated in Figure 4.1.

4.1.2 Total Cases of Disable Condition in Registry System

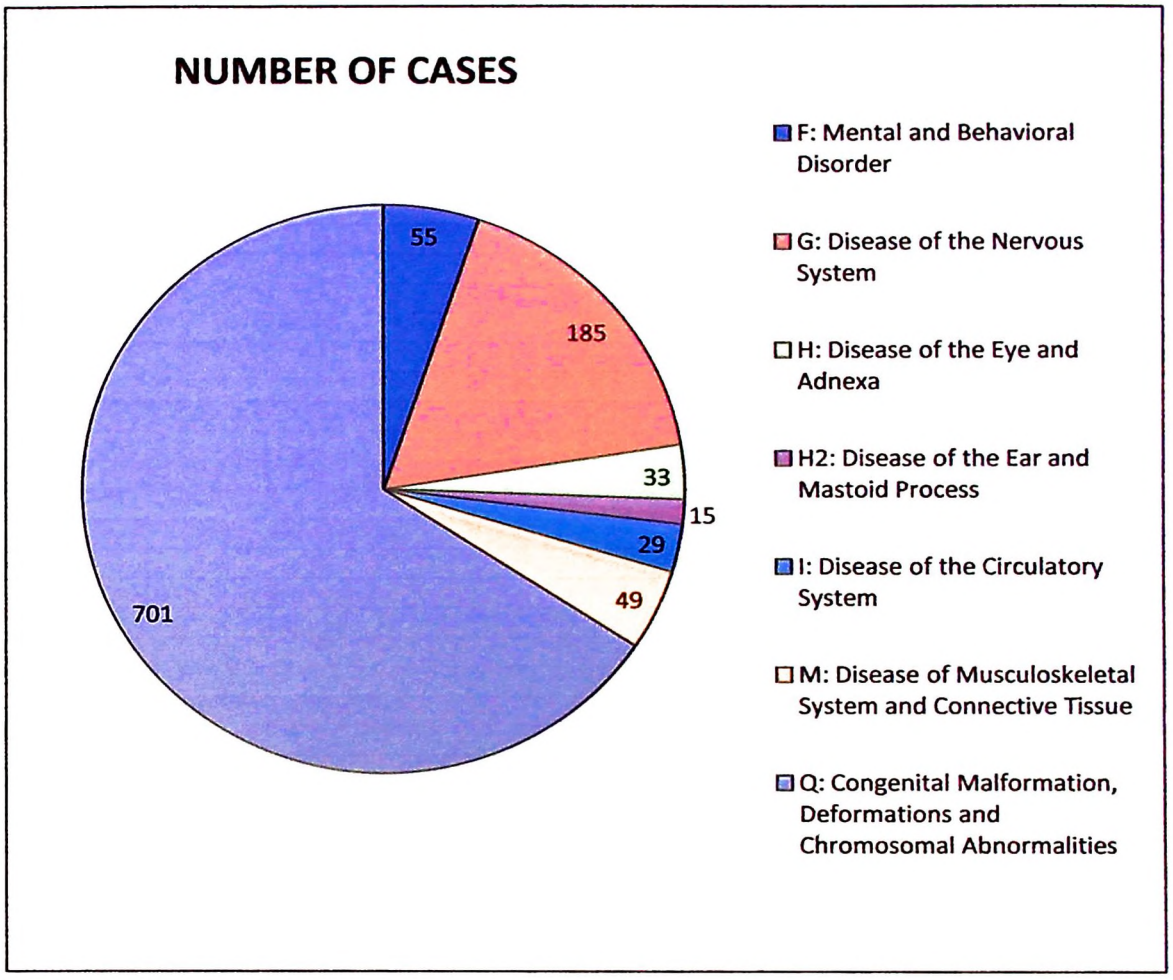


Figure 4.2: Total cases of disable condition reported in Hospital USM

The most cases reported were admitted were children who had been diagnosed a congenital malformation, deformations and chromosomal abnormalities, which are 701 cases (66%). In ICD-10 coding, this condition is coded as Q. The second highest cases that have been admitted were children who have disease of nervous system or coded as G in ICD-10, which 185 cases (17%). There were also 55 cases (5%) and 49 cases (5%) categorized under mental and behavioral disorder (F) as well as disease of musculoskeletal system and connective tissue (M) respectively. Furthermore, there were 33 cases (3%) of

disable children that have disease of eye and adnexa (H). In addition, there were 29 cases (3%) of disease of the circulatory system (I). The lowest cases reported in HUSM inpatient registry is children who were admitted because disease of ear and mastoid process (H2), which were only 15 cases (1%) in the whole year 2011.

4.1.3 Distribution of Disable Condition

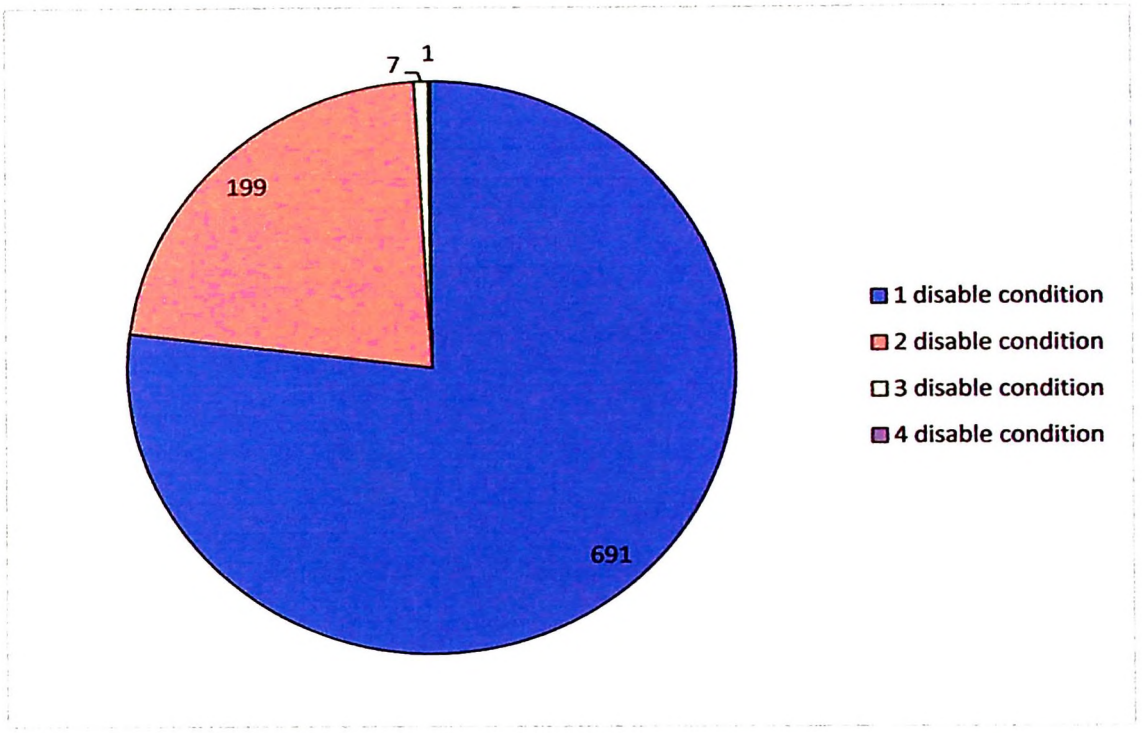


Figure 4.3: Distribution of children with disabilities according to number of disable condition

There are a few disabled children that were admitted because they only have one disabled condition and also a few of them that were admitted because of more than one disabled condition. Out of 898 disabled children in inpatient Hospital USM's registry, there were total 691 disabled children (77%) that were admitted because of only one disabled condition followed by 199 children (22%) with two disable condition. In addition, there were 7 children (1%) with combination of three disable condition. Only 1 child that has combination of four disabling condition.

4.1.4 Single Disabling Condition

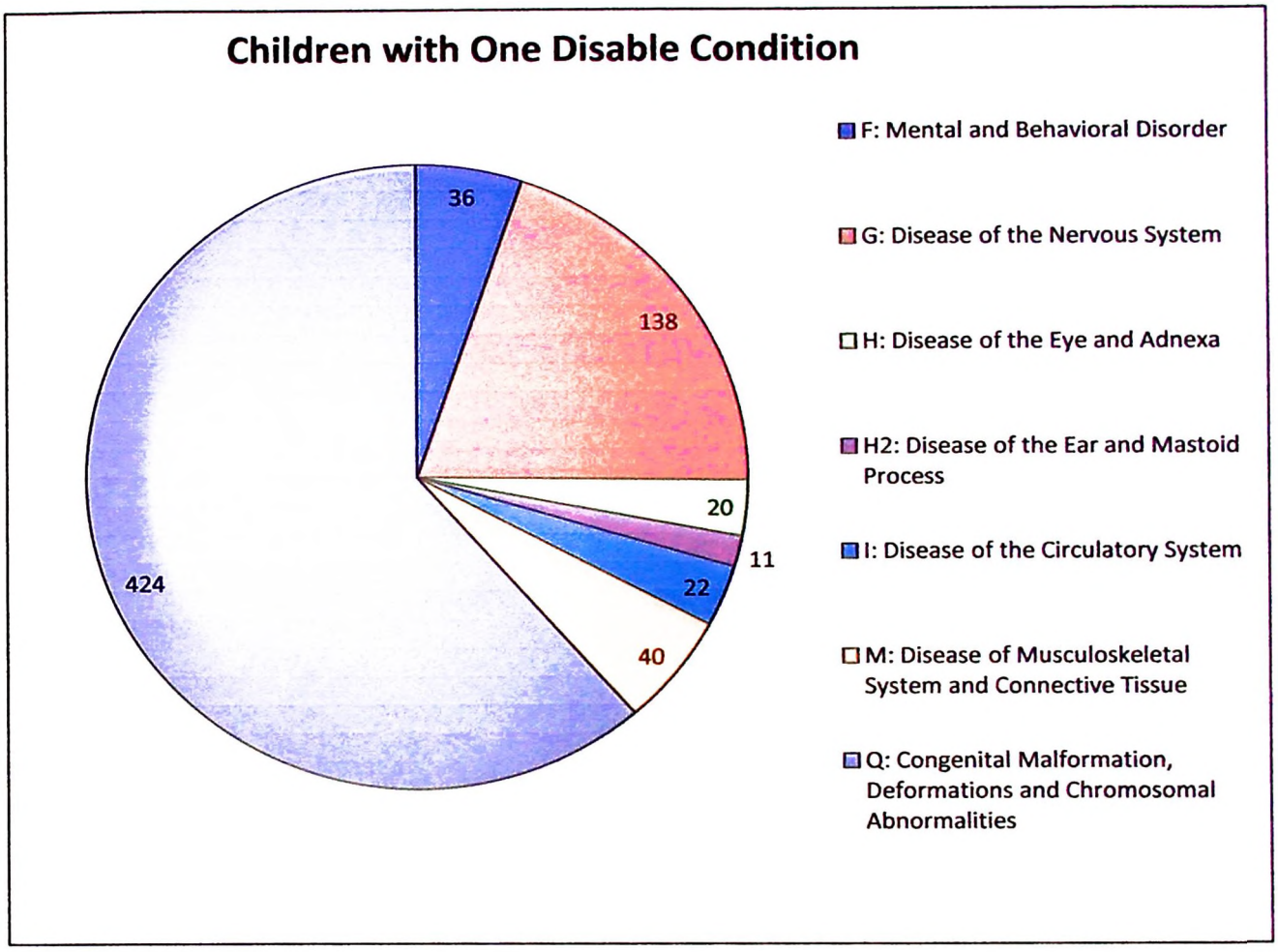


Figure 4.4: Number of children with one disables condition

There were total 691 disabled children that were admitted because of only one disabled condition. 424 of them were (61%) reported have congenital malformation and chromosomal abnormalities (Q). In addition, 138 disabled children (20%) were admitted because of disease of nervous system (G) while 40 disabled children (6%) were admitted because disease of musculoskeletal system and connective tissue (M). There are also 36 disabled children (5%) and 20 disabled children (3%) that have been admitted because of

mental and behavioral disorder (F) as well as disease of eye and adnexa (H1) respectively. Diseases of the circulatory system (I) affect 22 children (3%). The lowest numbers of children admitted were children who have disease of ear and mastoid process (H2), which are 11 children (2%).

4.1.5 Combination of Two Disabling Condition

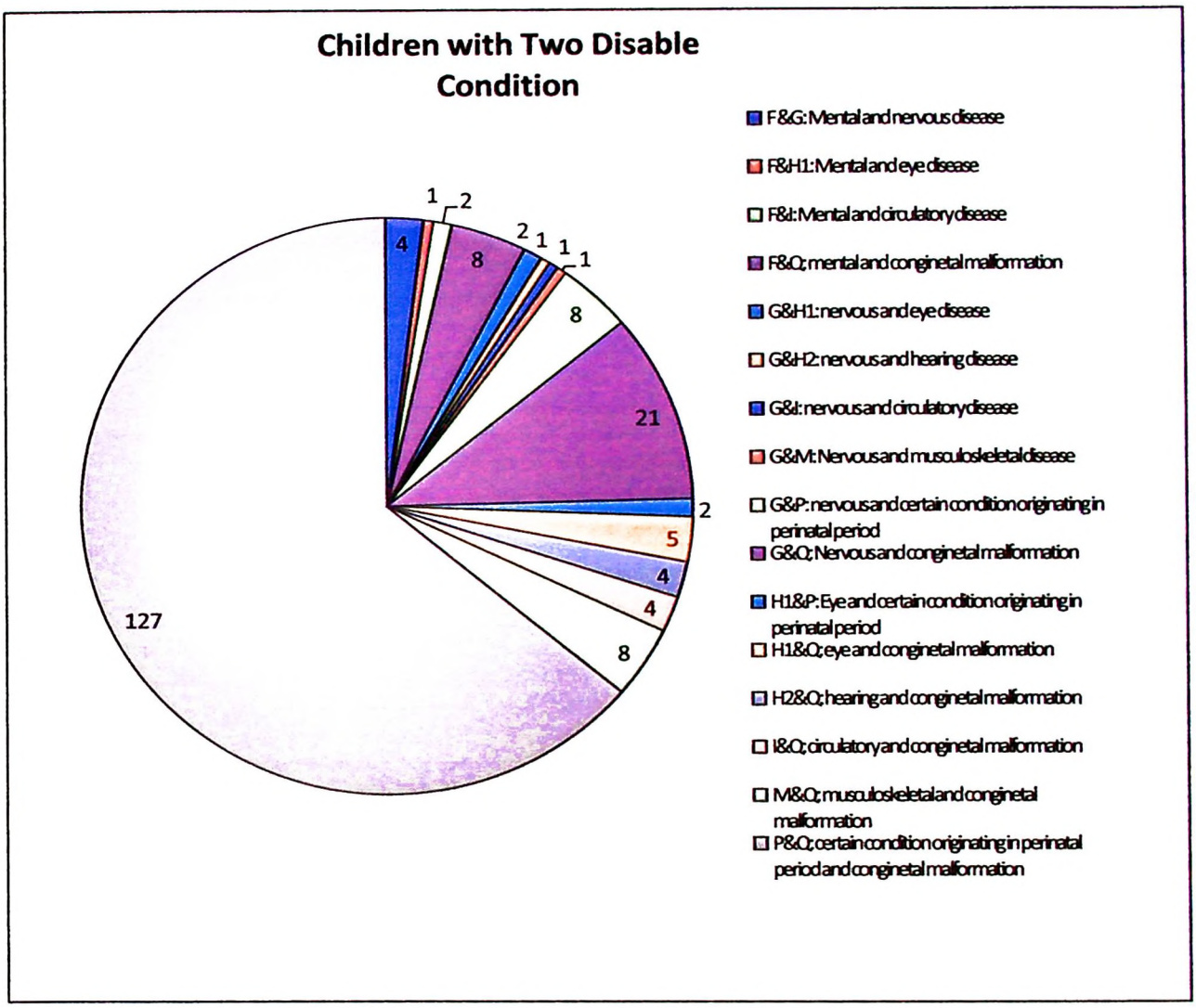


Figure 4.5: Number of children with two disabling condition

There were 199 disabled children that were admitted because of combination of two disabling conditions. Out of that, there are 127 of them (64%) were admitted because they have combination of disease categorized as P and Q condition. In addition, there are 21 disable children (11%) and 8 disable children (4%) who have combinations of diseases categorized under G and Q as well as G and P respectively. 8 children (4%) were admitted because they've combination of disease categorized under F and Q as well as M and Q.

Besides, 5 children (3%) were admitted because they have combinations of diseases categorized under H1 and Q. 4 children (2%) were reported have combinations of diseases categorized under H2 and Q, F and G as well as I and Q respectively. Meanwhile, there were 2 children (1%) that have combinations of diseases categorized under G and H1, H1 and P as well as F and I. 1 child (1%) was reported has combination of disease categorized as F and H1, G and I, G and M as well as G and H2 respectively.

4.1.6 Combination of Three Disabling Condition

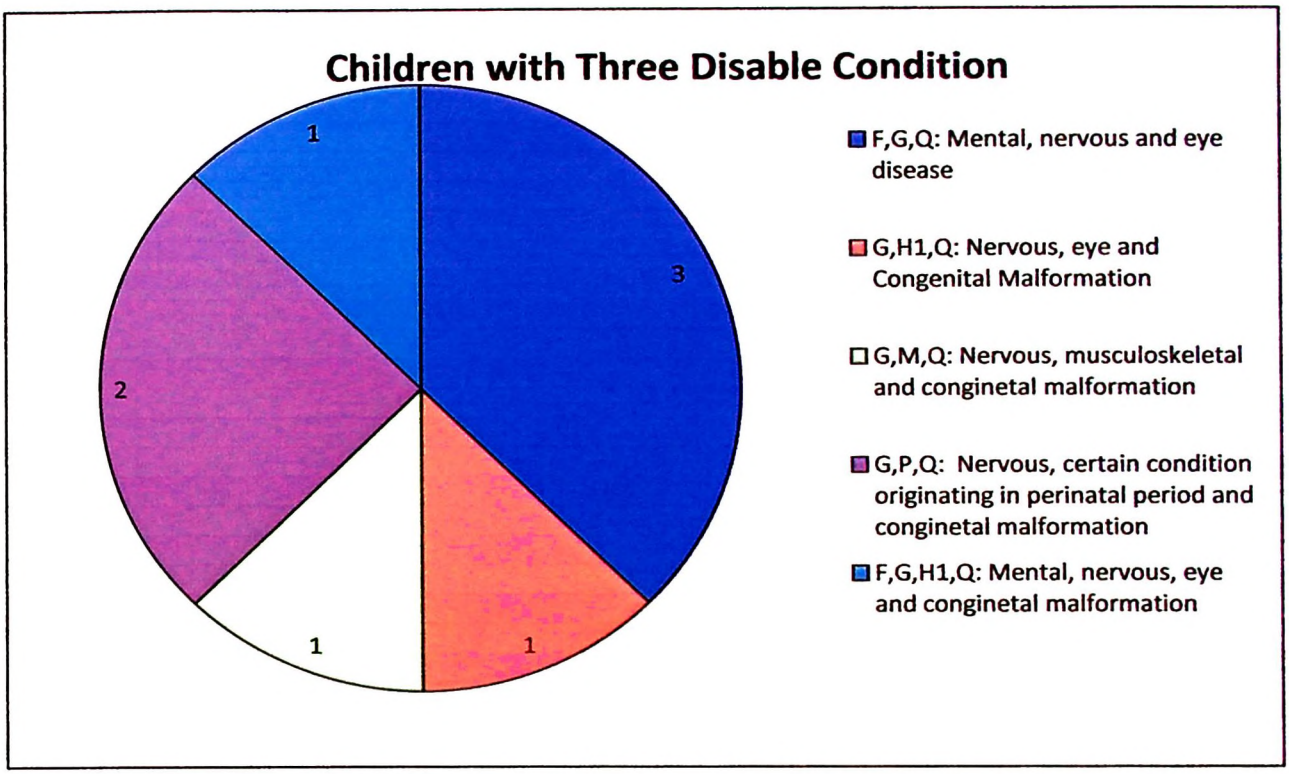


Figure 4.6: Number of children with three disabling condition

There are 7 disabled children that were admitted because of combination of three disable condition. 3 of them (37%) were admitted because they have combinations of diseases categorized as F, G and Q. In addition, there were 2 children (25%) that were admitted because of having combinations of disease categorized as G, P and Q. The rest of them have combination of disease categorized as G, H1 and Q as well as G, M and Q. Meanwhile, there is only 1 (13%) children who has combination of 4 disease categorized as F, G, H1 and Q.