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Research Article

TOWARD THE OPTIMAL MEDICAL SERVICES BASED ON INFORMATION SYSTEM: A NEW TAXONOMY OF DOWN SYNDROME BASED ON THEIR NEEDS OF HEALTHCARE SERVICES

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ABSTRACT

It can be noticed, recently, the important role of information system to enhance the life style of people with disability. Therefore, it can be motivating for all researchers to set a road map for developing and designing special system for them. For this reason, the authors present this article as a first step to develop a new health system for Down syndrome and increasing the role of information technology by setting a new taxonomy for individuals with Down syndrome based on their needs of healthcare services.

The methodology of this study is to present a short introduction of Down syndrome and the role of the World Health Organization. Followed that, conducting literature review to cover and identify the common health problems that faces individuals with Down syndrome. Finally, present the proposed taxonomy for these individuals.

INTRODUCTION

Down syndrome (DS) is a type of genetic and chromosomes disorder that affects the stages of social developments of individuals diagnosed with it. It is found by John Langdon Down in 17th century. DS appear around in one out of 700 of babies born (Megarbane *et al*., 2009). This disorder affects the health condition of the individual diagnosed with it and limits their ability to live normally (World Health Organization1, 2017). The physicians classified DS into three types, Trisomy 21, Translocation and Mosaicism with 94%, 4% and 2% of cases respectively (Kazemi *et al*., 2016).

The international classification of Diseases (ICD) is established by the World Health Organization (WHO) as a tool to diagnose diseases and manage the health status of countries (World Health Organization2, 2017). The first role of ICD is to classify the diseases that cause deaths. This classification can be a base for a government to establish other classifications that are related to health scope: such as the hospital records, medical payments, and other classification to manage the medical process (Moriyama *et al*., 2011). Many countries depend on the ICD-10 to classify the diseases. However, the WHO plans to transfer to the 11th Revision of the international classification of diseases by 2018 (World Health Organization2, 2017).

The main objective of information system is to manage data that relates with organization by collecting, processing, transferring, and decision-making related to it (James *et al*., 2007). Therefore, we can conclude that the data are the main building blocks of a work, and that clear-data can contribute to guarantee the success of any system. Data classification is an extremely important step to reach clear-data (Golfarelli *et al*., 2009). For example, classifying the medical data as public, secure, high risk, top secret, etc.

Health Information System (HIS) is an example of the impact of information system in health-care scope. It helps to enhance this scope by optimal collecting, storing, retrieving, transferring and decision-making of health-care issues (Cliff, 2012).

Unfortunately, the HIS currently does not perform the tasks that observers are looking for, it is only limited to filling medical records, data storage, retrieval and transfers. This means, it is working as a "data-driven" instead of "action-driven" (Lippeveld *et al*, 2000). This work leads to more problems such as poorer data quality, gathering data was irrelevant, lost time for gathering and feedback, and lack the experience to use this data.

For these reasons and the reason of the health-status of DS, the authors tried to prepare this article. The main objective of this article is to re-try to classify the health problems of DS's, to

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make these medical data clearer and allow using it to design a new medical system for them.

The methodology of this article is to survey several literatures that discuss the health-problems of people with DS and see the classification of these health-problems according on ICD-10. As a result, we propose a new taxonomy for DS in order to meet their needs of healthcare services. Finally, to propose this taxonomy to become a basic used in designing new health system for DS, the structure and components of the new system will be the subject of the next study.

Identify Health-Problems of People with ds

In the beginning, the authors want to mention the health status of the Iraqi people according to the annual report of 2016 (Ministry of Health / Environment of Iraq, 2017). The total number of life-birth inside Iraq was 994404 persons, with 2.5 percentages of congenital malformations per 1000 live births. Moreover, the percentage of DS birth is 2.3 of babies with congenital malformations. The Ministry of Health identifies DS according to the ICD-10 (Code Q-90). In addition, to the birth statistics report, a death statistic report shows there are 14011 deaths. The reasons of deaths as per the Ministry of Health classification include the Ischemic heart disease (ICD-10 Code: I20-I25)), heart failure (ICD-10 Code: I50), respiratory and cardiovascular disorders specific to the perinatal period (ICD-10 Code: P20-P29)), and congenital malformations for neonates (ICD-10 Code: Q00-Q99) are 8.38, 8.23, 4.83, and 7.02 respectively. Nevertheless, they do not mention particularly anything about the percentage of died people with DS. In addition, this report lacks any particular information about the health status of people with DS and the most common health-problem that they face. This satisfies what the authors mention in the introduction, "It Is The Time To Increase The Interest In The Health Status Of People With Ds".

Although the life expectancy for people with DS is increased, they are still facing health problems (Marshall *et al*., 2015). In the following, the authors summarize most health-problems related to DS.

Hearing loss

Hearing loss is one of the most common diseases that DS face. It occurs in around 75% of them with different reasons (Bull, 2011; Smith, 2001). This condition can lead to difficulty in their speaking ability (Sacks, 2003).

According to ICD-10, this disease is describe in chapter 8 with codes from H60 to H95. For example, the chronic ear infection that occurs in the middle ear is a big problem for DS. The Obstruction of Eustachian tube is one of this factors that are cause by compression, Stenosis, or stricture of the Eustachian tube. This disease can be found within ICD-10 in code (H68.1) as a part of diseases of middle ear and mastoid. This disease if not controlled earlier can cause in a rupture in the eardrum (Nightengale *et al*., 2017; World Health Organization3, 2017).

For this reason, the physicians recommend redo the auditory testing every two years (or as necessary) for DS to have a control of their hearing (Hildmann *et al*., 2002). For example, the organizers of Special Olympics Games in Germany-2004 and Japan 2005 used special healthy-hearing program to have a control of the Athletes' hearing status, but only 60% of the participant passed this test, which refers that disabled people need this test all the time (Kumar *et al*., 2008 Neumann *et al*., 2006).

Vision Diseases

The vision problems within DS are increasing with age. Although this medical condition is common for more than 60% of people with DS (such as cataracts, near-sightedness, and involuntary eye movements), the medical interventions included use glasses and eye-surgery to help to improve their vision (Bull, 2011).

Eyes diseases described in chapter 7 in the ICD-10 (World Health Organization3, 2017). One of the most common of the vision diseases is cataracts; it is a cloud over the lens in the eye that leads to a decrease in vision (Body, 1996). It is coded according to the ICD-10 as H25, and divided into several parts to describe its reasons, such as senile incipient cataract (H25.0), senile nuclear cataract (H25.1), senile cataract, morgagnian type (25.2), senile cataract, unspecified (H25.9), and describe other senile cataract (H25.8). In addition, other eye diseases are "crossed" eyes (H50.0), astigmatism (H52.2), and short and long sightedness (Myopia (H52.1) and Hypermetropia (H52.0)) (World Health Organization3, 2017).

Many authors submitted articles about the relation between DS and eye diseases. Haargaard and her partner presented an article about the DS and the early cataract, to estimate the cataract and DS among the Danish children, and they show that there are 29 of 1027 cases with DS and concluded that 1.4% of them needs surgery to recover this problem (Haargaard *et al*., 2006).

As we mention above, the early medical interventions involving surgeries can help DS to eliminate or control this medical condition. In addition, the AAP recommends that infants with DS examined by a pediatric eye specialist during the newborn period, and then have vision exams regularly every two years (Bull, 2011).

Obstructive Sleep Apnea

Sleeping is an indicator of the good health of the human. Therefore, guarantees obtaining a good and sufficient sleep will help eliminate health-problems related to it. At the same time, many sleep problems can appear especially for people with DS. This condition can affect their behavior and the ability to learn (Buckley, 2000).

The health-problems that are related to sleep disorder were described in ICD-10 within chapter 6 (Diseases of the nervous system, section: Episodic and paroxysmal disorders) with code G47 (World Health Organization3, 2017).

Obstructive sleep apnea is one of the most common sleep disorders that face people with DS (ICD-10 code: G47.3). It occurs in up to 50% of them (Bull, 2011). The physical characteristic of DS such as large tongue and maxillary hypoplasia, in addition to other factors like obesity can contribute to appear and increase this condition (Skotko *et al*., 2017). The physicians use a sleep study (Polysomnography) to diagnoses and estimate the sleep status of patients, this test helps to collect the related data such as the value of obtaining Oxygen during the sleep (Skotko *et al*., 2017; Rosen, 2012; Trois *et al*., 2009).

Finally, the physicians recommend monitoring people with DS, especially if they have abnormal physical features, by making a sleep test for them every two years (Bull, 2011).

Heart Defect

One of the most difficult health problems that affect people, especially who have a DS is heart defect. This health condition was described according to ICD-10 in chapter 9 (Diseases of the circulatory system; code: I00-I99) (World Health Organization3, 2017). This condition can cause death if not diagnosed earlier (Esbensen, 2010). Therefore, the AAP (American Academy of Pediatrics) recommend making the intervention and diagnosis at the birth-date for people with DS like echocardiogram (Bull, 2011).

This condition can appear in around 50% of people with DS with different types of it (Bull, 2011). For an example of this disease, a Mitral valve prolapse (code: I34.1 according to ICD-10) can affect 57% of people with DS and needs a continuous treatment and tracking (Smith, 2001). Another example according to a survey in the Saudi Arabia between 2001- 2014, shows that Atrial Septal Defect (ICD-10 code: I51.0) was found in around 33.5% of heart defects (Alsuhaibani *et al*., 2016). In Turkey, heart defect is also one of the critical and higher-percentage diseases which people with DS face, it is found in around 72% of people with DS with different types (Mihci *et al*., 2010).

In addition, it can appear in a relationship between heart defects and other diseases. For example, a survey studied in Brazil, shows that there is a relation between heart disease and severe infections for a child with DS (Faria *et al*., 2014). In addition, a heart defect has a relationship with snoring, sleep apnea, and needs to be continuously monitored (Dooley, 2016). For these reasons, the physicians recommended making a comprehensive test if the patient has one kind of a heart defect (Faria *et al*., 2014; Dooley, 2016).

In conclusion, the heart disease is one of the common diseases for people with DS, and needs earlier and continuous intervention (Guralnick, 2010; Guralnick, 2011).

Digestive Diseases

As we mentioned before, individuals with DS have many health problems, one of these problems is digestive problem (occur in about 12% of DS) (Bull, 2011). This condition was described according to ICD-10 in chapter 6 (code: K00-K93) (World Health Organization3, 2017).

This disease can lead to blockage in stomach and intestinal, and it will be necessary to make an operation to recover it (Koros *et al*., 2017). In addition, swallowing difficulties and physical features can contribute for this health-problem to appear such as: long tongue and poorer mouth's muscle (Carson *et al*., 2000). High prevalence of GERD is also one of the common digestive problems that face DS. It occurs in about 12% of the individuals with DS, so monitoring this disease especially at birth can help to a diagnosis of this disease (Massimo *et al*., 2017).

Because the digestive diseases are one of the diseases that cause death, therefore, the periodic follow-up can help to detect diseases (Esbensen, 2010).

Dental and Periodontal Diseases

Dental and other problems in the periodontal are also common for individuals with DS (Smith, 2001). This health problem is described according to ICD-10 in chapter 6 (code: K02) (World Health Organization3, 2017).

Because of the mental case of people with DS, this condition may become one of the big challenges, and leads to teeth loss (Pilcher, 1998). Therefore, the healthcare providers and the family doctors can recommend and contribute towards encouraging for continuous reviewing for the dentist (every 6 months) to control the dental status of people with DS (Smith, 2001).

Thyroid Gland Diseases

Thyroid gland is one of the largest endocrine glands that are responsible of secretion of two important hormones (Thyroxine T4 and Triiodothyronine T3), these hormones have a direct effect on the functions of the body such as: growth, and full biological processes in the human body (hall *et al*., 2015). This medical condition was described according to ICD-10 in chapter (code: E00-E07) (World Health Organization3, 2017).
The thyroid hormone abnormalities can affect the individual with DS in a percentage 4-18% (included all types of thyroid disease like: congenital hypothyroidism and hyperthyroidism). This percentage seems as normal. However, it takes importance in many articles, because it is a sensitive medical condition (Bull, 2011; Boron *et al*., 2012).

Melinda J. and *et al*. use retrospective records of individuals with DS in one institute, and they estimated the thyroid abnormalities. They concluded that this condition can affect all human and those with DS in the same percentage, and the gender or obesity are not related to this percentage. Finally, they recommended checking the thyroid - stimulating hormone level especially for babies and retrying it annually (Bull, 2011; Pierce *et al*., 2017).

As we mentioned, Hypothyroidism is a kind of Thyroid disease that affects individuals with DS. This kind of disease has a relationship with the heart disease. Maire *et al*. presented an article to show the relation between Thyroid disease and rising of the heart pulses (Percy *et al*., 2017).

Other Problems Individuals with DS face

In this part, authors try to summarize other health-problems that related to DS.

Alzheimer: is a common health-problem individual with DS face by age 65, it can appear in about 80% of them and lead to developing dementia (Head *et al*., 2012). Therefore, the Committee on Genetics of the American Academy of Pediatrics (AAP) recommends the physicians to continuously track for this health problem in adulthood. This tracking started by estimating their change of behavior, identifying losing-function, monitoring decrease of Intelligence Quotient (IQ) test, in addition, to monitor historically their activities by a family doctor. Therefore, retrying the IQ test annually is important especially to those who are over 40 years old (Bull, 2011).

Blood disease is also a common health-problem that individuals with DS face with in all age periods and it increases

10 times more than with normal people. Leukemia, anemia, and polycythemia are the most common blood disorders they face with. Therefore, physicians recommend blood tests must be retried annually (Bull, 2011; Khan *et al*., 2011).

Infections with the individuals with DS are 12 times more than the others face this health-problem, caused by immune system for them. Therefore, physicians recommend their continuous monitoring to provide treatment quickly in emergency case (So *et al*., 2007).

Obesity is one of the issues most common for individuals with DS, we can see it in around 45-79% for male, and 56-96% for female. The unstable diet, having some health-problems (like eating behavior, unstable metabolic rate, hypothyroidism, and low exercise), in addition to abnormal physical features, helps to increase the incidence of obesity. Therefore, the physicians recommend a continuous monitoring to control this condition (Esbensen, 2010).

Finally, it must be mention that, there are other health-problems affecting individuals with DS not listed in this article. For example, cancer occurs in low percentage, so breast exam is important to be done annually especially for females; epilepsy also occurs in low percentage and a neurological exam is needed frequently (Cohen, 2003; Desai, 1997; Cohen *et al*., 2003).

Motivation

As mentioned above, DS have huge problems in their life especially in their health status, and there are no medicines that can cure these problems. Therefore, the rehabilitation can be helpful for them; this rehabilitation can be in their life style and the strategies of their treatment. Here the need of information system to develop and enhance this field has emerged. The guide for families of children with DS from the American Academy of Pediatrics (AAP) has been develop to manage their life style by classifying them by age (before birth, first month, first year, between 1 to 5 years, between 5 to 13 years, and over 13 years old). This taxonomy consists of the important issues that faced them in every age group. This guide consists of the common health-problems for this group, including optimal health activities and tests, which might need (Cohen, 2003; Cohen *et al*., 2003).

In addition, the responsibility to provide healthcare services is resting upon all of us (the medical service providers, the society) (Marshall *et al*., 2015).

AAP classifications, ICD classification by the WHO and the responsibility can be a motivation for us to thinking of developing a new taxonomy for DS according to their needs of healthcare.

RESULTS

According to above, we can mention that individuals with DS face many health-problems. These problems range from normal to severe and need a special way of treatment (according to the symptoms and affected body place). Therefore, we can make taxonomy of individuals with DS according to their need of the healthcare. This taxonomy divides the health-problems as the following (Table 1. shows the proposed taxonomy):

Health-Problems that Need to be Early Detected

As we showed, there are some health-problems, which are commonplace for individuals with DS like heart defects, digestive diseases, and thyroid gland diseases. Therefore, the physicians recommended making specific-tests for these diseases at birth to evaluate the effectiveness of the human organs and detect the health problems if occurred.

Health-Problems that need Routine or Continuous Treatment

As we showed, there are some health-problems, which need a long-time treatment (chronic diseases) which occur as a result from heart defect, digestive diseases, diseases related to obesity, and infections, and these diseases need specific tests. Therefore, the physicians recommended making these tests continuously. This approach can help to monitor the health-status of individuals.

Health-Problems that need an Immediate Intervention

As shown above, some health-problems occur as an emergency case like heart frailer, some types of digestive diseases, some types of blood diseases, and infections. These diseases can lead to death, so the physicians recommend immediate intervention for the control of these cases.

Health-Problems that need an Annual Reviewing

As shown, there are some health-problems, which need to make medical review and test annually, to assess the work of human organs, such as hearing abilities, the vision status, and evaluate their sleeping. Therefore, the physicians recommended making specific tests for these diseases such as auditory tests, ophthalmologic exams for keratoconus, sleeping test annually (one time every one or two years).

Table 1 Taxonomy of DS according of healthcare needs.

Medical-review / test / diseases	Early detect	Routine (continuous)	Immediate (emergency)	Annual	
				1 year	2 years
Auditory testing of hearing Loss					✓
Vision tests (like: Ophthalmologic exam for keratoconus & cataracts)					✓
Evaluation of Sleep Apnea					✓
Heart tests (like: Echocardiogram)	✓	✓	✓		
Medical review for digestive disease	✓	✓	✓		
Dental reviewing (Twice)				✓	
Thyroid functions test	✓			✓	
Alzheimer checking (especially over 40 years old)				✓	
Blood disease test			✓	✓	
Infections test		✓	✓		
Obesity		✓			

CONCLUSIONS

The importance of this article is to retry classification of individuals with DS based on their needs of healthcare. This can be a basic approach to manage their information to set an optimal health system for monitoring and tracking their health status. From this article, it can be conclude the following:

ICD did not consider the individuals' needs of healthcare especially those with DS. Therefore, there is an urgent need to a taxonomy of DS that focuses on DS healthcare needs and can help providing optimal healthcare services.

This taxonomy can be a base for design a new system for DS, by identify the optimal data about the DS needs.

This taxonomy helps to increase the investment IT in health-field, by use the modern IT to monitor and track them and leads to enhance this field in the future.

This taxonomy can contribute to provide healthcare services at the real time.

This taxonomy contributes to reduce the impact of all diseases of disabilities around the world and help making a world-without-disability by managing the life-style of individuals with disabilities

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