PARENT'S EXPERIENCES OF DAILY LIFE HAVING A CHILD WITH DOWN SYNDROME IN COSTA RICA
ABSTRACT

Background
Out of all chromosomal disorders, Down syndrome is the most common. Being a parent to a child with this condition comes with unique challenges and can be a life-changing experience, as the child will require special attention and interdisciplinary care throughout the life span. Limited research has been done regarding parents' experiences of daily life with a child having Down syndrome, and this study is an attempt to contribute to the understanding of this phenomenon in general, and in Costa Rica in particular.

Aim
The aim of the study was to describe parents' experiences of daily life with a child having Down syndrome in Costa Rica.

Method
A qualitative interview study with a semi-structure was used as approach together with qualitative content analysis. An inductive approach was used for the analysis. Six parents in San José were interviewed for the study.

Result
Parents' experiences of daily life with a child having Down syndrome in Costa Rica was associated with various aspects, some in general and some more specific. The general were positive and negative experiences, whereas the others were more focused on specific areas regarding the daily life and Costa Rica as a country.

Conclusion
Parents in Costa Rica tend to have similar positive and negative experiences when comparing to other studies of this phenomenon. The findings suggest that Costa Rica is a country with deficiencies when it comes to the social, legal and educational system.

Keywords: Down syndrome, Parents, Daily life, Costa Rica, Nursing
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BACKGROUND

Down Syndrome

There are around 750-1000 different genetic-chromosomal disorders leading to intellectual disabilities (Hodapp, 2007). The term intellectual disability is defined as limitations in intellectual functioning and adaptive behaviour (Katz & Lazcano-Ponce, 2008). Out of all chromosomal disorders, Down syndrome is the most common (Hodapp, 2007). It occurs in one out of 800-1000 live births, and the prevalence is known to be similar within all ethnicities (Choi, Lee, & Yoo, 2010). The word “syndrome” means a collection of disorders and associated symptoms that occurs together, which means it’s not a disease (James, Jackson, & Ashwill, 2013). During the last decade the birth prevalence of people with Down syndrome has remained relatively stable (Määttä, Määttä, Tervo-Määttä, Taanila, Kaski, & Iivanainen, 2011) and the life expectancy has improved significantly. The life-span has doubled meaning that individuals with Down syndrome now can live into their 50s or 60s (Hodapp, 2007).

History

In 1866 the British physician Langdon Down reported the clinical description (Mégarbané, Ravel, Mircher, Sturtz, Grattau, Rethoré, Delabar, & Mobley, 2009) of the physical characteristics associated with the syndrome (van Gijn & Gijselhart, 2011). At that time Down syndrome went by the name “mongolism”, since the facial features of these individuals were considered similar to the Mongolian people. In year 1965 Mongolia sent a delegation to the World Health Organization (WHO), as a request to stop using the terms “Mongoloids” and “Mongol” to describe individuals with this form of disability. WHO decided to change the name to Down syndrome, after L. Down, and thereby it becomes the new accepted terminology. Today the term “mongolism” is removed from most references (Global Down Syndrome Foundation, 2014-04-02). In 1959 the third copy of the 21st chromosome was discovered confirming the chromosomal abnormality (Mégarbané et al., 2009). Despite the increased genetic knowledge the complete ethiology and pathology of Down syndrome is not clear (Betz & Nehring, 2010). Researchers are trying to identify candidate genes that may be involved in the formation of the specific features of this condition. The aim is to contribute to the development of targeted medical treatments for individuals with Down syndrome (Mégarbané et al., 2009).

From the late 1800s to about 1970 people with intellectual and developmental disabilities was segregated from society. Institutionalization was the norm (Betz & Nehring, 2010) and according to Anderson (2014) the decision to institutionalize individuals with intellectual disabilities was often influenced by the physicians’ advice. In the 1970-ties the deinstitutionalization began and over the years the stigma has changed (Betz & Nehring, 2010), and nowadays institutionalization is less common (Anderson, 2014). Today physicians are still considered as an important source of knowledge regarding possible medical conditions and the degree to which children with Down syndrome may be able to live independently as adults (Anderson, 2014). Legislation together with changes in social attitudes has lead to an increasing acceptance and thereby created a greater potential for richer lives, not only for people with Down syndrome but for all people with intellectual disabilities (Carr, 2008). Today most families raise their child at home until early adulthood (James et al., 2013), and children with Down syndrome are integrated into society, which has enhanced by educational initiatives, family support, health care
knowledge, diagnostic improvements, housing options and support systems (Betz & Nehring, 2010).

Every year on March 21 The World Down Syndrome Day takes place. It’s a global awareness day, which has been officially observed by the United Nations since 2012. This day is aimed to highlight and raise awareness of what it means to have Down syndrome, what Down syndrome is and how these individuals play a vital role in the communities and our lives. The desire is to create a global voice for advocating for the inclusion, rights and well-being of people with Down syndrome (World Down Syndrome Day, 2014-03-18).

Chromosomal alternations
In general chromosomal abnormalities are common and about 50 percent are spontaneously aborted prenatally. They often cause major defects because they involve many missing or adding genes (James et al., 2013). There are three different chromosomal alternations that cause Down syndrome: trisomy (nondisjunction), translocation and mosaicism (Briggs, Mason, Ovchinnikov, Wells & Wolvetang, 2013). Trisomy, or Trisomy 21 as its colloquially called, accounts for approximately 95 per cent of all cases of Down syndrome. The name Trisomy 21 refers to that there are three copies of chromosome number 21, bringing the total number to 47 (Ghosh, Feingold, & Dey, 2009). It’s caused by an error in the cell division called “nondisjunction”. The other two alternations are fairly rare occurring. In translocation a part of the 21st chromosome brakes of during cell division and get attached to another one, usually number 14. The total number of chromosomes in the cell is 46, but still gives the characteristics of Down syndrome (National Down Syndrome Society, 2014-03-29).

Mosaicism is a different form of Down syndrome in a way that not every cell has the third copy, and thereof the symptomatology or phenotypic features are fewer in general (Betz & Nehring, 2010). Individuals with this karyotype tend to show a higher level of intellectual functioning (Bittles, & Glasson, 2004).

Diagnostic criteria and risk factors
The diagnosis of Down syndrome can be determined both in the prenatal and postnatal period. Both are done through a chromosomal analysis via blood, and in the prenatal period it is combined with an ultrasound (Betz & Nehring, 2010).

To diagnose Down syndrome in the postnatal period, there has to be a certain number of features combined. Thereof there is not a singular feature that is characteristic. There are many different features of Down syndrome that covers the entire body, and each individual has a different set of features. Some of the most common are flat occipital area, false fontanel, loose skin at nape, small and shortened ears, oblique narrow palpebral fissures and short extremities. These features may be present in a newborn without Down syndrome, and therefore it is essential to complete the diagnosis with a chromosomal analysis (Betz & Nehring, 2010) so called karyotype (National Down Syndrome Society 2014-03-29). Through a blood sample and by using special tools the doctor can photograph the chromosomes, and then confirm the diagnosis (National Down Syndrome Society, 2014-03-29).

One of the main risk factors associated with Down syndrome is maternal age. If the mother is 35 years old the risk of having a child with Down syndrome is 1 in 400, and then increases significantly, although most of these children are born by mothers under 35.
Another factor that increases the risk is if one of the parents has genetic predispositions (James et al., 2013).

**Intellectual impairment**
Social, intellectual and language dysfunctions are commonly associated with Down syndrome (James et al., 2013). Studies report that individuals with Down syndrome have social integration difficulties, such as developing a social network. Although research has shown that individuals with Down syndrome demonstrate greater socio-emotional skills compared to other intellectual and developmental disabilities (Hippolyte, Iglesias, Van der Linden, Barisnikov, 2010). The intellectual impairment varies depending on which type of chromosomal disorder the child has (James et al., 2013). Regarding language skill, children with Down syndrome are likely to have difficulties obtaining all aspects of the language system. This due to limitations in long- and short-term memory and sometimes a more specific language-learning deficit (Kaiser & Roberts, 2013).

**Medical conditions and health care**
Down syndrome is associated with many physical and clinical characteristics. More than half of the children with the diagnosis require surgical intervention as treatment for one or more of the clinical characteristics (Harris, Abbott, & Jukes, 2012). Common surgical treatments is often required due to cardiovascular, digestive, musculoskeletal and genitourinary problems. Furthermore individuals with Down syndrome are at high risk for having hearing loss, visual impairment, infections, hypothyroidism, epilepsy, depression and Alzheimer’s disease (Määttä et al., 2011). Some of the conditions can be present at birth whereas others appear later in life, and the severity varies depending the individual (Betz & Nehring, 2010).

Hospitalization of children with Down syndrome is common during their first years (So, Urbano, & Hodapp, 2007). Two health care guidelines has been published concerning individuals with Down syndrome, *Guidelines for individuals with Down syndrome: 1999 Revision* and *Health supervision for children with Down syndrome*. Both are directed to healthcare professionals and outline medical considerations from birth to early adulthood (Hodapp, Miodrag, Goldman, & Urbano, 2010). According to Hodapp et al (2010) little is known if they receive adequate and consistent healthcare. Furthermore, the research is limited regarding the needs of individuals with Down syndrome and their experiences of system of care (Minnes & Steiner, 2009).

**Being a parent of a child with Down syndrome**
To have a child may be one of the most important events in life. Parenting comes with a great readjustment, as the child requires much attention (Annerén, 1996). Today one can make accurate prenatal diagnosis of Down syndrome, although most families learn about the diagnosis after birth. During pregnancy many express their concern about possible defects of their unborn, but to actually have a baby with some kind of disability is often difficult and unexpected. There are many factors affecting the parental adaption such as severity of the child’s condition, the existing level of family function, the availability of social support, cultural background, income level and the attitude of the healthcare providers (Choi et al, 2010).

Raising a child with Down syndrome comes with unique challenges (Betz & Nehring, 2010) and may be a life-changing experience (King, Zwaigenbaum, Bates, Baxter, & Rosenbaum, 2006). It requires increased physical, emotional and financial demands.
Children with Down syndrome will require special attention and interdisciplinary care throughout the life span (Betz & Nehring, 2010). According to Siklos and Kerns (2006) early intervention treatment programs are important for these individuals regarding the long-term prognosis. Different services may be required such as financial supplements, transitional services, social services and preventive or corrective medical care. This may be overwhelming (James et al., 2013) and many parents may feel anxious about their capacity of caring for their child who may have various physical and intellectual needs (Betz & Nehring, 2010). This can have a great impact on the family functioning, as well as daily life, holidays and other activities (Povee, Roberts, Bourke, & Leonard (2012). Research shows that the impact on the family can vary depending on type of disability, personality of the affected child, family style, parental well-being, mental health and attitude (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008).

Mothers and fathers react differently in having a child with Down syndrome. Several studies have found that mothers experience more stress and express greater needs for familial and social support. The fathers on the other hand tend to be more concerned about the economical aspects around the care of the child and what it will mean for the family as a whole. In general both parents show higher levels of stress on measures of depression, health, parental competence and role restriction compared to parents of typically developing children (Hodapp, 2007).

**Theoretical framework**

**Daily life**

Doris Carnevali (1996) has created a model that describes a structure for daily life, functional ability (inner resources) and outer resources. According to Carnevali (1996) the health of the individual and quality of life depends on whether there is a balance between the requirements of daily life and resources available. This applies regardless the functional health status of the individual. Thereof the definition in the concept of health is based on the presence of balance and not whether the individual is ill or not.

In order to achieve balance one has both inner and outer resources. The inner resources are divided into: strength, endurance, sensations, frame of mind, knowledge, motivation, courage, skills and communication. Outer resources are also important in a sense that they can be the cause of balance or great imbalance. An individual with some form of disability can be able to attain a satisfying and effective daily life if there is access to appropriate and sufficient outer resources. Carnevali (1996) defines outer resources as: residence, neighbourhood, communication facilities, people, material, technical aids, technology, transportation, economical assets and even pets can be a resource (Carnevali, 1996).

According to Carnevali (1996) daily life contains different requirements, which are activities/experiences, events/experiences, expectations/obligations, environment, values, beliefs, customs and traditions. Different activities and experiences may affect or get affected by the health condition of the individual. The experience and reaction of an activity or event varies in meaning and significance, which means that each individual experiences similar situations in different ways. Previous events and experiences also have an impact on the reactions and behaviour of the person in certain situations (Carnevali, 1996).
Carnevali (1996) describes that expectations and obligations are often created by the individual himself, but also by other people. The expectations regarding the individual often involve the degree of dependence/independence or about the sense of control. Other aspects connected with expectations are daily life, work and responsibility for other people. Sometimes the expectations from other people and the ones of the individual are incompatible in a changing health situation, thereby health related complications easily arise. Every individual is aware of their own values, beliefs, customs and traditions, but when it comes to actually describe them it’s often very difficult. They become very clear in a changed health situation, and affect the behaviour and reactions of the person (Carnevali, 1996).

The concept environment includes residence, school and working place which all are central parts of daily life. Restrictions in the functional ability then become crucial for the well-being of the individual (Carnevali, 1996).

**Nursing and Down syndrome**

According to the International Council of Nurses (ICN): Code of Ethics for Nurses, nursing care is respectful of and unrestricted by considerations of age, colour, culture, disability or illness. Nurses also render health services to the individual and family as well as the community and coordinate their services (ICN, 2014). According to Carnevali (1996) a nurse must be able to describe specific nursing problems, which they refer to treat and diagnose. In order to do this it requires a structure for development of the specific problem areas. The model of Carnevali (1996) may be used as a tool for the nurse to plan the care treatment. Carnevali (1996) means that the nurse’s role is to help individuals and families in finding the balance between the requirements of daily life and resources available. By identifying and assessing both inner and outer resources the nurse can create different nursing diagnoses, and at the same time determine the functional ability of the individual.

All children’s nurses are likely to care for a child with Down syndrome during their careers (Harris et al., 2012). The nurses play an important role in providing health care to children with different developmental disabilities (Sanders, Kleinert, Free, Slusher, Clevenger, Johnson, & Boyd, 2007). Having Down syndrome may lead to several medical conditions (James et al., 2013) and to have a child with this diagnosis can be a source of distress for the parents (Van Der Veek, Kraaij, & Garnefski, 2009). Studies have shown that initial interactions with health care workers may influence the parent’s reaction to their child’s diagnosis. To be able to provide support for the parents, the nurse first has to evaluate his/hers own feelings and attitude toward Down syndrome (Choi et al., 2010). By adopting a non-judgmental and a compassionate approach to care, the nurse can reduce the level of stress (Harris et al., 2012). Hall, Neely-Barnes, Graff, Krciek, and Roberts, (2012) mean that nurses should do an assessment of the parents, looking at their experience and level of parental stress, and not only focus on the specific diagnosis. According to Siklos and Kerns (2006) the interaction with the family should focus on the needs of the parents and to help them cope with their child. Reasonable adjustments should be made such as make time with the parents to talk about the diagnosis (Harris et al., 2012).
Costa Rica

Costa Rica is a small middle-income country (Unger et al., 2008) located on the isthmus that connects North and South America (Koutnik, 2009). There are 4.6 million inhabitants whereof the majority lives in the cities. In the heart of the country lies the capital city San José. The city is located on a tableland 1200 meters above sea level surrounded by mountains. Weather and climate are tropical but can vary depending on the altitude and if you are at the coast or inland. In the sixteenth century the country was colonized by Spain, thereof the main language is Spanish. Costa Rica declared their independence from Spain in 1821 and became a part of the Central American Federation. In 1838 Costa Rica left the federation and became the independent republic it is today (Utrikespolitiska Institutet, 2010).

Costa Rica is a country with a strong social and economical development (Utrikesdepartementet, 2013) and it’s considered unique for having an enduring democracy and the highest standards of living in Central America (Vorhees & Firestone, 2006). Along with the economic and social development, society has changed. More women are entering the workforce, family size has shrunk and more people are entering higher education. Education is a main priority for the country and the people. The public school system is free which contributes to a high literacy rate (Vorhees & Firestone, 2006). The government has made great investments in the education sector as well as in poverty alleviation. Today one fifth of the populations is counted as poor. The majority of the working population is in the service sector whereas the other part is within industry and agriculture. Costa Rica has a well developed welfare system which contains healthcare and pensions (Utrikespolitiska Institutet, 2010). Over the years Costa Rica has made great progress within the health sector. According to Unger et al., (2008) their health care system is based on solidarity and equity. Virtually all Costa Ricans have access to health centers and the healthcare in the hospitals maintain high standard (Utrikespolitiska Institutet, 2010).

Costa Ricans are very proud of their country and sees it as an oasis of calm, as it has flourished without an army since 1949 (Vorhees & Firestone, 2006). However, criminality, violence and drug trafficking are increasing (Utrikespolitiska Institutet, 2010). Costa Ricans are well-mannered, friendly and to them the family is the nucleus of the social and cultural life. Like many of the industrialized countries, families in Costa Rica have an average of 2.2 children (Vorhees and Firestone, 2006). Abortion is not officially legal and one of the reasons may be that the majority of the population is catholic, although they see every child as a blessing (Koutnik, 2009).

Down syndrome in Costa Rica
In Costa Rica there are approximately 400.000 individuals with some kind of disability (Gatjens, 2001) and approximately one percent have Down syndrome (Federación Iberoamericana de Síndrome de Down, 2014-03-18). The country has an advanced legislation regarding people with different types of disabilities. However, the compliance is limited which results in violation against human rights such as cultural, social and economical. According to Gatjens (2001) these individuals are still exposed to social marginalization and discrimination.

In 1996 Costa Rica enacted the law number 7600; Law on Equal Opportunities for Persons with Disabilities. This law is aimed to improve the living conditions in this sector of the
population within areas such as access to education, health and rehabilitation, employment, public transportation and so forth (Gatjens, 2001). According to Gatjens (2001), Executive Director of the Inter-American Institute on Disability, there is a non-compliance regarding these areas. Rejections of students with disabilities, such as Down syndrome, continue to occur in both public and private schools. Furthermore, the construction of buildings, physical environment and public transport are not in favour for all individuals, which make it difficult and discourage the entry of people with disabilities into the classroom. There is also prejudice among teachers regarding these individuals. The lack of accessibility is fairly widespread within several areas such as access to places for sports and in cinemas, libraries, museums and theatres.

Costa Rica has made great progress within the health sector, compared to other Latin American countries. Despite these achievements there are still significant gaps within the field of rehabilitation for children, since it’s more designed for adults. The majority of the health services are centralized in the capital city San José, which affects the quality of care and rehabilitation for these children in rural areas (Gatjens, 2001).

Gatjens (2001) means that there has been some progress, but that the progress is limited and materializes very slowly. In general the government and public institutions prevail focus on disability, in an old-fashioned way in terms of paradigms characterized by charity and pity.

Organisations
The organization Asociación Síndrome de Down Costa Rica (ASIDOWN) is the main support network for families of individuals with Down syndrome (ASIDOWN, 2014-03-18). They are a member of the Federación Iberoamericana de Síndrome de Down, which is a federation created with a desire to strengthen the cooperation between various Latin American countries as well as different national federations (Federación Iberoamericana de Síndrome de Down, 2014-03-18).

ASIDOWN is a non-profit organization that supports the auto determination of the individuals and their families. They promote the inclusion of people with Down syndrome from birth in all areas of the country, including health recreation, education and work. Their vision is to be able to support individuals with Down syndrome and their families for their development, opportunities, rights and responsibilities as all other citizens, to ensure that they are included in all social systems. Their work is still in progress in order to receive support from all parts in the Costa Rican society (ASIDOWN, 2014-03-18).

The study problem
Of all the chromosomal disorders Down syndrome is the most common genetic cause of intellectual disabilities. The research history dates from the 1860s onward. One might draw the conclusion that the field is well informed about these individuals and their parents, but unfortunately large gaps remain. In countless studies the syndrome has been used as both “contrast” and “control” group for other disability conditions (Hodapp, 2007). Further on much research has focused upon the impact of parents and their experience of having a child with an intellectual disability, and lately the experience of the siblings has been investigated (Mulroy et al., 2008). The focus has typically been on the negative aspects of raising a child with an intellectual disability rather than the positive aspects it can provide, but the interest of the positive contributions has increased. Studies seldom bring up the
benefits concerning the family as a whole, the parenting role or society (King, Zwaigenbaum, Bates, Baxter, & Rosenbaum, 2011). According to Hoddapp (2007) there has been a relative inattention to families of individuals with Down syndrome compared to other intellectual disabilities. In contrary to the past, children with Down syndrome live together with their parents, which highlights the need for ongoing research about these phenomenon (Mulroy et al., 2008).

This study took place in Costa Rica, which is a country that has undergone great social, economical and environmental changes over the years (Utrikesdepartementet, 2013). The study would be able to contribute to the understanding of daily life with a child having Down syndrome in general, and in Costa Rica in particular. It would benefit the community, school and the healthcare in a way of more knowledge about the diagnosis, and the experiences of the parents and their children. Accordingly, the aim of this study was to describe parents’ experiences of daily life with a child having Down syndrome in Costa Rica.

AIM

The aim of the study was to describe parents’ experiences of daily life with a child having Down syndrome in Costa Rica.

METHOD

Study design

A qualitative method with semi-structured interviews was used to conduct the study. Qualitative research is aimed to describe human experiences where the data is gathered from spoken or written words (Polkinghorne, 2005). The purpose of semi-structured interviews is to explore experiences and attitudes by using a flexible topic guide that provides a loose structure of open-ended questions (Pope, van Royen, & Baker, 2002). This method was considered appropriate in relation to the study’s aim.

In the study three languages were involved: English, Spanish and Swedish. English was the language of the study while the interviews and the transcriptions were made in Spanish. Swedish is the author’s first language. Dictionaries (Nordstedts Lilla Spanska Ordbok, 2011 & Nordstedts Engelska Ord n.d.) as well as a proof reader was used to be able to gain a full understanding of the text and to translate into English. In the result the citations were the original with a free translation in English.

Inclusion criteria

The survey groups were Costa Rican parents living near the capital city San José, since it was the most convenient for the author and considering the study’s dimension. The inclusion criteria were that the parents had to be Costa Rican citizens and have at least one child with Down syndrome. The child had to be between 0 to 18 years old, in order to be considered as a child. Another criteria were that the interviewees had to have Spanish as native language. All criteria were made based on the aim of the study.
Interview guide

The questions for the interviews were designed in Costa Rica with advice from local contacts, and were audited and approved by the principal at the school where the interviews took place. The formulation of the questions was discussed with a proof reader to make sure they were grammatically correct. The interview guide contained nine questions and a few simulating follow-up questions (Appendix A, I) to be able to develop the answers of the informants. The interview guide was designed to receive narrative answers by using open questions.

The interviews were performed addressing various aspects of having a child with Down syndrome. Question one was aimed to make the participants feel comfortable and was used by the author as a way of adapting to the culture. The experiences of the parents were evoked by asking: “Would you like to share some of your experiences of daily life with a son/daughter with Down syndrome? “. The majority of the questions contained one or several of the keywords such as: Down syndrome, experiences, daily life.

Pilot interview

Two pilot interviews were made to test the interview guide and to see if the questions were adequate in relation to the study aim. The result of the first pilot interview was not entirely satisfactory. The author decided to do another interview using the same questions, to see if the responses were due to the specific informant or if the questions were unclear. The result of pilot interview number two were of contentment, and therefore it was considered unnecessary to change any of the questions. Both pilot interviews were included in the result, which is in agreement with Granskär & Höglund-Nielsen, 2012.

Data collection

Since the study took place in Costa Rica preparations were required in order to find the parents to be interviewed. Through personal contacts the author came in contact with a principal at a school, which educates children with Down syndrome and provides different kinds of therapies for these individuals. At the meeting with the principal all information about the study was given in form of two letters in Spanish, one for the principal (Appendix B, II) and one intended to the parents (Appendix C, III). In the letters the study was described and all the essential information was given. The letters were intended to be a request for permission and participation. A thank you letter from Sophiahemmet Högskola and a diploma from SIDA:s Partnership, describing a Minor Field Study, were also given. The principal approved the request to perform the study.

The author desired to have informants outside the ordinary interview circuit in order to give the study a wider material. Several other contacts were asked if they knew parents having a child with Down syndrome. The same information letter along with the diploma were given to these contacts, although there was no recurrence and therefore the school was used as base to find the informants for the study.

At the school there were parents waiting outside for their children. The informants for this study were selected from this group and as well when the parents left their children at the school. The selection was made using both purposive and convenience sampling (Anderson, 2010). In the selection both mothers and fathers of different ages were
The data was collected through six semi-structured interviews with narrative questions as described by Henricsson (2012). In an interview, and in any conversation, there are three different parts fulfilling the communication. These are the verbal, the vocal and the visual parts, where the vocal and visual are non-verbal. Within the verbal part there are the locution (the way of expression), illocution (the technique) and per locution (the pronunciation) whereas there are many more within the non-verbal. As much as 93 per cent of the communication consists of non-verbal things such as body and eye movement, facial expression, meaning of space, touch, handshake and vocal factors such as tone, clarity, non verbal utterances and silence. Knowing these facts it requires even more active listening in a cross-cultural dialogue than in a dialogue with someone from the same culture (SIDA Partnership Forum, Alex Muigai, 2014-03-12).

The first three interviews were conducted on separate days while the last three were conducted on the same day. Altogether it took two weeks to do the interviews. The interviews were conducted different times during the day and one parent at a time was interviewed. Before each interview the author was presented as a Swedish nursing student preforming a bachelor thesis. The participant read through the information letter and received an oral presentation of the project.

Each interview took between 15 to 60 minutes and they were all audio tape-recorded with the permission from each informant. Age and gender of the parent and the child were written down and every interview was named; Informant A – F.

Data processing

All the interviews were transcribed ad verbatim in Spanish, using the recording material. Every interview had to be listened to several times for them to be transcribed, since it was sometimes hard to hear or distinguish the exact words. In the transcriptions pauses and laughs were included. The transcriptions were made shortly after the interviews, the same day or the day after. By doing so the author had the interviews fresh in memory, which was important in the transcription process, considering the different language (Granskär & Höglund-Nielsen, 2012).

Data analysis

In the processing and analysis of data a qualitative content analysis was made as described by Graneheim & Lundman (2004). An inductive approach was used for the analysis of the collected data under the purposes described by Thomas (2006). Before the data analysing began, the transcriptions were read several times in order to learn the content of the material, and to obtain a sense of the whole. When a good knowledge and understanding of the data was achieved the text from each informant was organized into different content areas. These content areas became different units of analysis. Every unit was divided into meaning units that were condensed, meaning that unnecessary words and pauses were removed. By using condensation the meaning units decreased in size but still preserved the
core (Graneheim & Lundman, 2004). The condensed meaning units were abstracted and labelled with a code as according to Graneheim & Lundman (2004). The codes were compared based on differences and similarities and were sorted into different main categories. To create a better structure the codes were compared and organized a second time under each main category, which created subcategories.

The author chose citations that were considered most appropriate in illustrating the different categories. Citations from each informant were represented in the composing of the result. More citations were used under the categories linked most to the aim, in order to increase the diversity.

**Credibility**

Reliability and validity are important terms within qualitative research in a way that they assess the credibility (Anderson, 2010). Both depend on the quality of data collection, management and identification or interpretation of meaning (McMillan, 2009). Reliability refers to the stability and reproducibility whereas validity relates to the genuineness and honesty of the data (Anderson, 2010). Within qualitative research reliability cannot always be judged, since the settings may be unique to particular contexts and therefore makes it difficult to replicate the study (Pope et al., 2002). According to Pope et al., (2002) qualitative methods score high regarding internal validity. By examining and document what individuals mean when they describe their experiences, attitudes and feelings, it provides an accurate representation of the phenomenon.

To establish credibility it is important to choose the most appropriate method for data collection (Graneheim & Lundman, 2004). Qualitative research looks at life experiences and therefore the collection instrument have to capture this accurately, so that it assumes to disclose these experiences and thereby guarantee validity (Fontanella, Campos, & Turato, 2006). Another way of enhancing the credibility is to select the most suitable meaning units (Graneheim & Lundman, 2004), which the author attempted in the highest degree during the analysis of the transcriptions.

To present the result the author used representative citations under each category, which illuminates the differences and similarities between the categories. By using citations it enhance the credibility as it gives the reader an opportunity to examine the accuracy of the interpretations of the interviews (Granskär & Höglund-Nielsen, 2012). The citations describing the experiences may be transferable to other groups of parents having children with different intellectual disabilities.

If more than one author had made the study, it automatically would have enhanced the credibility, as several authors are able to contribute to different perspectives in the analysing process. As an attempt to establish a high credibility the author made sure that the reader is able to audit the influences, events, and actions of the author by describing them well in the study. Throughout the study the author had a critical thinking and was aware that interviewing is an evolving process containing new insights and reflections. The author attempted to use accurate and peer reviewed references that were up to date, which contribute to the credibility and makes the study topical.

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Ethical aspects

The first ethical aspect that was taken into account was the importance of informed consent. Informed consent provides assurance that the participants neither are coerced nor deceived (O'Neill, 2003). It is an ethical and legal requirement in studies involving human beings (Benitez et al., 2002). The participants gave an oral consent of participating in the study. Through the information letter and the oral presentation the participants received the knowledge of that participating in the study was completely optional and that they could end it at any time. The participants decided the amount of information they wanted to share, as a result of the narrative questions.

According to DiCicco-Bloom and Crabtree (2006) there are four issues related to the interview process: Reducing the risk of unanticipated harm, Effectively informing interviewees about the nature of the study, Protecting the interviewee’s information, and Reducing the risk of exploitation.

To protect the participants from unintended harm the interview questions were overlooked and approved by the principal at the school, to ensure that they weren’t going to bring up delicate subjects.

All information about the study such as aim and method was described in the information letter, together with their specific rights if they decided to participate or not. Information on how to contact the researcher was also written in the letter. To ensure that the participants understood the meaning and aspects of the study, the author gave an oral presentation, which in turn created an opportunity for the participants to ask questions.

To reduce the risk of the interview to become a friendly conversation, the author was presented as a student doing a bachelor thesis. By using this kind of presentation the author was open regarding the role of interviewer, which according to Gillham (2008) is an important part in the interviewing process. A question of the participant’s names was made out of politeness, but the names were never written down to ensure the confidentiality.

All ethical principles in relation to confidentiality of data regarding the participants were adhered. During the transcriptions the interviews were listened to in private with headphones, to prevent spreading personal information. The transcriptions, audio files, notes and other personal information concerning the informants were stored with access only to the author.

RESULT

The study’s aim was to describe parents’ experiences of daily life with a child having Down syndrome in Costa Rica. The result is based on experiences of six parents between the ages of 21 to 50 years. The children with Down syndrome were of different genders and aged between six months to nine years. The results of the study will be presented in different main categories. Some of the categories have sub-categories (Tabel 1.). Under each category there are appurtenant citations in Spanish with a free translation in English. The names mentioned in the citations are fictional.
## Tabel 1.

<table>
<thead>
<tr>
<th>Main categories</th>
<th>Sub-categories</th>
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<td>Positive experiences</td>
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### Positive experiences

The interviews were initiated with the exhortation; “Tell me something positive about your son/daughter”. Many of the parents described specific positive characteristics of their child while others talked about the child’s development. One of the mothers’ responses was:

“Positivo? Bueno todo. Toda la alegría que me ha traído…a la familia. Es el primer hijo de mi matrimonio verdad…este…ha sido todo positivo…bastante lleno de alegría en la casa.”

Positive? Well everything. All the happiness he has brought to me…to the family. It’s our first son right…well…everything has been positive…he has brought a lot of joy to the house.

In general all the parents shared positive experiences. For one of the parents having a child with Down syndrome was life changing because it motivated her to continue her studies. She describes it as:

“/.../cuando el nació…para mí es un mentor en mi vida…pude salir del colegio…me gradué de secretaria…solo me falta el bachillerato y quiero seguir estudiando por que…de yo antes es que…era como un poquito flojilla verdad…y a ellos…mí hijos en especial Daniel…desde que el nació fue el que me ayudó las ganas de continuar y las fuerzas de continuar…”

/.../when he was born...for me he is a mentor in my life...I left school...I got a secretary degree...now I just need to finish high school and I want to continue with my studies because...before...I wasn’t a very good student...and for them...my sons especially Daniel...since he was born he was the one who helped me with the desire to continue and the strength to continue...

Most participants mentioned positive characteristics that they saw in their child and expressed gratefulness that the child developed well and was in good health. There was awareness that things could be a lot worse as one informant said:

“El es muy inteligente gracias a dios...aunque no fuera siempre verdad...uno como madre los alienta...pero es que lo importante es que el se vaya desenvolviendo y mas independiente cada día...”
He is very intelligent thank God…however it hasn’t been like that always…as a mother you encourage them…but the important is that he keeps growing as a person and becomes more independent every day…

Negative experiences

During the interviews the informants also shared some negative aspects of having a child with Down syndrome. One mother experienced some difficulties regarding her daughter’s behaviour. She wished her daughter could behave better towards people at home and in the street:

“/…/bueno su conducta…entra bien y después es casi como…se cambia de genio…y entonces es que quisiera que ella tuviera una mejor conducta…con la gente de afuera y con…con las de la casa…por que a veces se comporta mal…”

/…/well her behaviour…it starts good and then it’s almost like…her mood changes…and well I’d like that she would have a better behaviour…with people and with the ones at home…because sometimes she misbehaves…

Another informant mentioned that it’s sometimes difficult because one doesn’t have a life like the ordinary:

/…/si ha sido en partes difíciles por que…uno no tiene una vida como el corriente verdad. Entonces que…mientras cualquier otro niño de su edad esta durmiendo tranquilo en su cama…con el ha sido terapias para arriba y para abajo…”

/…/yes it has been partly difficult because…one doesn’t have a life like the ordinary. Then…while any other child at his age is sleeping quietly in his bed…with him it has been therapies here and there…

For one of the informants it was difficult to receive the news that the child had Down syndrome:

“/…/uno reacciona duro…yo como padre en estos momentos sentí algo duro…”

/…/you react strongly… in these moments as a father I felt something harsh…

Acceptance

One theme that was brought up by several of the parents was the acceptance of the child. Two of the parents indicated that there had been difficulties in the beginning to accept the child. Many of the informants mentioned that they had asked themselves the question “why?”. A parent expressed this as:

“Como padres…como hemos tenido un desarrollo emocionante muy fuerte…negativo claro…no puede ser…por que?..por que a mi?..estábamos en situaciones que uno a veces dice por que ahora?…”
As parents...as we have had a very strong emotional development...negative of course...it can not be...why?..why me?..we found ourselves in one of those situations when you say why now?...

Many of the other informants confirmed that they had asked the same questions, but they saw it as God’s purpose:

“/...bueno siempre se existe el preguntar “por que” verdad...de tener un niño especial. Pero yo se que Dios tiene un propósito con todo esto...”

/.../well there is always the question “why”... having a special child. But I know that God has a purpose with all this...

Costa Rica

Society
The interviews indicated that there are both positive and negative aspects of having a child with Down syndrome in the Costa Rican society, although the negative aspects and desires for improvements were highlighted. A parent described Costa Rica as a blessed country with many resources desired by other countries, and that there is a reason to be grateful for living there. The same parent also expressed the difficulties of incorporating these children in society:

“/.../en incorporarlos ahora en sociedad propia...es muy dificil...Costa Rica no cumple todavía...para mi no cumple...para mucho no cumple...”

/.../to incorporate them into the society...it is very difficult...Costa Rica still doesn’t comply...to me it doesn’t comply...it’s far from complying...

Many of the parents have a long route to the school, since the schools in their neighbourhood don’t have the proper resources for these children. One of the mothers expressed her dissatisfaction regarding the difference between the law 7600 and the reality. According to the law as a parent you should be able to choose the school you like for your child, but the reality is different:

“/.../supuestamente la ley 7600 dice que...que uno como padre decide en que lugar donde quiere que el niño de uno estudie y eso no es asi...por que si digamos aquí en la escuela especial no le dicen a uno usted se lo puede llevar allá a una escuela regular...”

/.../supposedly the law 7600 says that...that as a parent you decide where your child goes to school and that is not so...because lets say here at the special school they don’t tell you that you can take the child to a regular school...

In Costa Rica there is financial support available for these parents, although there were different directives from the informants. In the interviews it appeared different opinions regarding the existence of a specific pension for children with disabilities. The processes go very slow, one parent had been waiting for a year to receive a reply from the authority. Additional support was one of the things that was requested:
“De la verdad que se le ayudan mas…por que uno no se puede irse a trabajar por que tiene que…todos los días traerlos…que hubiera como una apoyo o asi…mas para uno…que estuvieran pendiente de darles como que… trabajar de noche o algo asi…a uno para poderse ayudar…”

Well to tell the truth that they would help more…because one cannot go to work because you have to…every day you have to take them to school…that there would be some kind of support…more for us…that they should take more action and provide us like … a night shift job or something…so you can help yourself...

Another aspect that was brought up about the Costa Rican society was the importance of money. According to the informant the Costa Rican people only see the things that indicates that the person in question has money:

“/…/por que aquí todo es el dinero…no se si usted lo ha visto…yo se que en todo el mundo no es pero en este país si es mucho…en ticos…nosotros como costarricenses…vemos solo el dinero…no vemos otras cosas…vemos la tecnología…vemos un carro…vemos una casa…vemos un montón de cosas…”

/…/because here everything is money…I don’t know if you have noticed…I know that it’s not like this in every country but here it means a lot…as ticos…as Costa Ricans…we only care about the money…we don’t care about other things…we look at the technology…we look at the car…we look at the house…we only see the material things...

The same informant meant that this kind of mentality contributes to the difficulty in integrate children with Down syndrome in society. Focus is on so many other things than these individuals and the government doesn’t have a great interest, as the informant said:

“A veces hay momentos cuando uno llora…en silencio…cuando usted dice “por que?””…”por que nació en esa sociedad?”…y el gobierno no le interesa…por que para tener una escuela como esa hay que gastar…es una inversión…en Costa Rica no toman ese carisma…y uno lo siente…y yo lo veo así…si que si hay muchas ayudas…pero uno ve realmente el interés…”

Sometimes you have those moments when you cry…in silence…when you ask “why?””...”why was he born in this society?”...and the government doesn’t have the interest...because to have a school like this one you have to spend…it’s an investment...in Costa Rica they don’t make that effort to have that kind of charisma...and you feel it...I perceive it like that...there is ...but you see the real interest...

**Health care**

Two of the parents mentioned factors regarding the healthcare in Costa Rica. One mother appreciated that the hospitals provide many different medical exams to check the heart, eyes and ears.

Another informant described the experiences of the situation at the delivery of the child, the reactions from the doctors and how the child later is treated when going to a hospital. Visiting a hospital the informant said that they are always prioritised and there were no dissatisfaction regarding the care of the child, although there had been some change in the approach from the health care workers since the child was younger:
“Siempre cuando vamos a llevarlo a un hospital...cuando vean a Gabriel siempre somos así...prioridad...siempre somos atendidos no lo puedo negar...de Gabriel siempre ha sido excelente...hasta donde se arregla los dientes...llega una diferencia por como...en general es que a mi es que...cuando ellos son pequeños son agradados...cuando lleguen a unos doce años y más adelante estas personas son apartadas...”

Every time we go to a hospital...when they see Gabriel we always are like ...priority...we are always attended I can’t deny...for Gabriel it’s been excellent...at the dentist as well...it comes a difference when...in general to me it is...when they are little they treat them nicely ...but when they reach the age of twelve and older these persons are excluded...

Attitude
One of the informants expressed that the society has opened up more, although there were frequent experiences regarding other people’s behaviour and attitudes towards their children. Many described that people would look at them in a certain way, sometimes with loathing, and one informant said that they would ask strange questions about the child. The informants made a connection between the difficulties of the child’s integration in society to the way people look at them and treat them. One mother wished for all parents to teach their children to treat individuals with disabilities as any other person. The problem, according to the mother, is that they look at these children as if they had a disease:

“.../la problema es que vean como así que pobrecitos que como si ellos tuvieran una enfermedad...y no es una enfermedad...supuestamente que uno se nació con una condición diferente...pero no es que tienen una enfermedad...”

“.../the problem is that they pity them as if they had a disease...and it isn’t a disease...supposedly that the person was born with a different condition...but it’s not like they have a disease...

Two parents also wished for their child to be able to go in an ordinary school for them to be influenced by the everyday behaviour in other children and thereby learn faster. They also thought it would be easier to integrate them in society, although they also saw the difficulties with this as it would require teachers with knowledge and who are patient:

“/.../para entrar en una escuela normal...pero para poder entrar en una normal tiene que ser una profesora o maestra que tenga así carisma...de entender...”

“/.../to go in a normal school...but to be able to go to a normal school there has to be a teacher that has charisma...that understands...

An additional connection was made between the way people behave towards these children and the level of knowledge of the condition. According to an informant the knowledge of Down syndrome, what it is and so forth, isn’t very satisfactory. A request for more public information that educates the people and make them less ignorant, as the informant expressed:

“/.../y si sería bueno como mas información para la población por que la gente si son ignorantes verdad...”
/.../and it would be good if there was more information for the population because the people are ignorant...

Daily life

Regarding the daily life of these parents they all had routines in the weekdays and tranquil weekends. Some keywords that emerged and fit in at each informant were early mornings, school, different therapies, waiting, going home, stimulation and staying home. Only one of the informants claimed to have a full time job. The same informant said it wasn’t easy to find a balance between the job and family life in relation of having a child with Down syndrome:

“/.../pero los primeros cinco años trabajaba para poder mantener una relación con mi familia cada tres/cuatro horas...dejara a mi trabajo para estar con el...dos/tres horas... perdí a un día a veces...”

/.../but the first five years I worked in order to maintain the relationship with my family every three or four hours...I left my job to be with him (the child) two/three hours...sometimes I missed a full day...

Much time was spent with the child during the day and weekly activities such as going to the park, buying an ice cream and socializing with other family members were common. Several of the parents mentioned that they put much effort in teaching their child to take care of themselves in order to be more independent in the future. Many informants also gave the sensation of having a special connection with their child as one of the single mothers describes it when talking about daily life:

“/.../todo lo compartimos juntas...y cuando la papa se lleva...me siento como me hace falta algo de...algo de...la mitad de ella se va...y yo me quedo como sola...y entonces...vamos al parque...los domingos...a veces mas...a veces al “Mas X Menos” a comprarle cosas...le compro un helado...”

/.../we share everything together...and when the father takes her with him...I feel like something is missing...like half of her goes away...and I’m being left alone...and then...well we go to the park...on Sundays...sometimes more often...sometimes we go to “Mas X Menos” (supermarket) to buy some stuff...I buy her an ice cream...

Resources

The word family was mentioned a lot during the interviews, although three of the informants were single moms. All three stated difficulties in being a single parent, and not only because of the child’s diagnosis but also since they all had more than one child. Five out of six mentioned that there were other family members who could help if necessary.

Four parents confirmed that they use to share their experiences with other families, at the school or at home. They ask each other for advice for example:

“/.../digamos este cuando empiezan a dejar sus pañales...como hizo una para que el otro aprendió...nos compartimos nuestras experiencias...desde los conocemos...de si todavía no come...como hago para lo otro aprenda a comer y así...”
Several parents mentioned the school and the teachers as an important resource regarding the child’s development. Many felt that the teachers have a good way of teaching their children and that they as parents have learned a lot from the school as one of them describes:

“/.../y aquí en la escuela le enseña demasiado a mi...y por eso estoy muy contenta...que la maestras ...que me han ayudado mucho...”

“/.../and here at the school they teach me a lot...and so I’m very happy...that the teachers...that they have helped me a lot...

When it comes to economy there were two of the informants that confirmed they received some kind of financial support, and one informant was still waiting for reply from the authorities. Regarding the other informants, one received alimony from the child’s father and had also applications in process at the authorities, one didn’t receive any financial support and one was unknown. One of the single moms describes her situation like this:

“/.../este no he recibido ningún subsidio por el estado o algo así...todas las vueltas que he hecho para eso...estaban negado y otras están en proceso...como una beca aquí en la escuela esta en proceso...eh...yo la traigo aquí pero de hecho es un tema muy conflictivo por que...este año ha sido muy difícil...y...lo único que tengo es la pensión del niño pequeño...”

“/.../I have not received any subsidy from the state or something like that...all the paperwork I have done...some of them have been denied and others are in process...like the scholarship here is in process...eh...I bring him here but the fact is that it’s a very problematic issue because...this year has been really difficult...and...the only thing I have is the subvention for the little one...

DISCUSSION

Result discussion

The majority of the parents reported positive experiences of having a child with Down syndrome. These were related to the child’s development, specific characteristics and other positive contributions, such as personal development. Similar positive experiences are seen in the qualitative study of King et al., (2011) where the parents celebrate what the child can do. There are similar connections regarding the negative experiences. In the qualitative study made by Povee et al., (2012) they explored the impact of having a child with Down syndrome on family functioning. Their findings were similar regarding the negative aspects as they were connected to the child’s social behaviour and that life itself is forever changed.

When it comes to Costa Rica as a country the informants weren’t completely satisfied.
The general message from the informants was that they face difficulties within society, the law system and financial support system. Believing the informants the image of Costa Rica given by Gatjens in 2001 has unfortunately been preserved. The informants confirm that the development is going very slow, that non-compliance exists, that Costa Ricans have a certain kind of attitude towards individuals with Down syndrome. In a study by Siklos and Kerns (2006) they examined parents’ of children with Down syndrome and their perceptions of needs, whether they are being met or not. One of their conclusions was that the majority of the needs weren’t met, indicating that the system isn’t providing adequate support. Thereby it seems to exist similar social deficiencies in other countries, and not only in Costa Rica.

The results suggest that there is a positive approach to the attention given in the school and the health care available in the capital San José. The school was considered a great resource in contributing to the child’s development at various levels and as well a source of support and knowledge for the parents. Two informants agreed with Gatjens (2001) regarding the achievements accomplished within the health care system. According to them the hospitals can provide adequate health care for their children, although there were mixed emotions regarding the attitudes and treatment of the health care workers.

In the structure for daily life of Carnevali (1996) there should be a balance between the requirements and resources available in order to maintain health and quality of life. By using inner and outer resources balance can be achieved. All informants seemed to possess several inner resources as described by Carnevali (1996) whereas the deficiencies appeared to be in the outer resources as well as within the environment. As mentioned above, in Costa Rica the presumptions don’t seem to be sufficient in order to fulfil the needs of these parents of children with Down syndrome.

As described in Vorhees and Firestone (2006) family is the nucleus of the social life and according to the informants an important resource in daily life. In general the daily life was characterized by routines quite similar as one imagine parents with children have, although only one of the informants mentioned having a job. Taking care of the child (or children) seemed to be equal to a full time job for the majority of the parents, since they spend much time on waiting outside the school as well as taking their child to different kinds of therapies. It seemed to be an accepted fact of daily life, even if one of the informants expressed a desire to at least have the opportunity to have a job.

Acceptance seemed to be a subject of importance for the informants to be able to continue daily life. Several studies have looked at different coping strategies when receiving the news that the child has Down syndrome. For some of the informants it has been difficult and for some quite easy to accept the child. Several informants used their religion to answer their questions of why they in particular got a “special child”. They seemed pleased believing it was God’s purpose and since it was meant to be it was also easier to accept. According to Pillay, Girdler, Collins and Leonard (2012) religion and spirituality has been useful as support during life changing events, as it is having a child with Down syndrome. It was expected that the participants would express themselves in a religious way, since Costa Rica is a religious country, but it was difficult to decide to which extent.

Findings from this study may be of use for the Costa Rican population and government as a source of knowledge about Down syndrome and what experiences these parents’ have and what they desires for their child and future. Health care workers may also find this
phenomenon interesting when it’s likely for them to meet individuals with Down syndrome at work. With knowledge from this study health care workers may be able to provide care in a more professional, supportive and adequate way, both regarding the interaction with the child and their parents. Through the personal experiences presented, other parents in similar situations may recognize themselves or gain new perspectives. Although the results may or may not be consistent given different attitudes, stigmas and more importantly: each person has their own values and beliefs. This is why the citations are of great importance since they emphasize the core of the result of which people can relate their own experiences.

In relation to the findings they were able to answer the aim in a diverse survey of different aspects regarding parents’ experiences of daily life having a child with Down syndrome in Costa Rica. The responses covered areas such as society, people’s attitudes, descriptions of daily life and experiences of being a parent to a child with this condition. The aim of the study is strongly connected to Costa Rica as country and the daily life of the interviewed individuals, which gives the study a cultural impress.

The author was fortunate that The World Down Syndrome Day occurred during the time spent in Costa Rica. At that day the author was at the school expecting some kind of activity or celebration to honour the day. However nothing was done to somehow affirm what day it was. Only a poster was put up announcing of some activities taking place somewhere in San José, organized by Asociación Síndrome de Down Costa Rica. The author’s reflection is that if a school like this, who is specialized to educate these individuals, doesn’t notice this day tells quite a lot. It confirms some of the statements made by the informants, that Costa Rica doesn’t make an effort to have that kind of charisma, which in turn highlights that individuals with Down syndrome are being excluded, even more. These parents are making different efforts for their children every day, and the author believes that they would appreciate something made for them in return.

**Method discussion**

According to Polkinghorne (2005) qualitative methods are used to clarify and describe human experiences. The collected data serve as evidence for the desired description (Polkinghorne, 2005). In this study interviews were used in a way of developing a deeper reflection of the participants’ experiences as expressed by Granskär and Höglund-Nielsen (2012). Since the aim of the study was to describe parents’ experiences of daily life with a child having Down syndrome, interview was considered an adequate approach.

Semi-structured interviews give the individuals an opportunity to use their own words through the narrative questions. The researcher adapts to what may come up in the interview, which makes it flexible, but still gives it a kind of structure (Henricsson, 2012). In the interviews the questions were asked in the order that felt natural in relation to the responses.

When it comes to the sampling, convenience and purposive sampling was used, which was due to the specific circumstances when performing the study. It was convenient for both the writer and the parents to do the interviews at the school since the participants had time and felt comfortable in the school area. The writer knew that the majority of the parents waiting outside had children with Down syndrome. The selection was made for the
informants to be of different ages and genders in order to achieve a higher credibility, and therefore the sampling became purposive.

The containing questions are of major importance since they determine the result. Different formulations may give different answers, which is why the adequacy of the questions should be tested in a pilot interview (Granskär & Höglund-Nielsen, 2012). In this case two pilot interviews were made since the first informant didn’t give very narrative answers. The result of the second interview was more satisfactory, which was why no changes were made in the formulation of the questions. Furthermore the interview questions had been approved both by the principal and the supervisor of the study. The first question was aimed to make the informant to open up and perhaps make it easier to share, if existing, negative experiences or difficulties. This question seemed to be unexpected for most of the informants, but the author experienced that it had the desired effect. Several areas were covered through the other questions and together they gave enough analysing material.

The interviews were conducted during different times of the day resulting in a varied amount of parents waiting outside. Furthermore, the parents visited the school for different reasons, since it offer both education and therapy. This created a large and diverse selection group. According to Graneheim & Lundman, (2004) choosing informants of different ages, genders and with various experiences increases the possibility to gain a richer variation of the phenomenon. To enhance the credibility the informants should have been recruited outside the ordinary interview circuit order to give the study a wider material. All participants in this study had the school in common, although they all had different backgrounds.

Interviewing six parents was considered sufficient in order to receive enough information to fulfil the aim in a credible way, and in relation to the study’s dimension. To avoid bias in the interviews all were made in Spanish. The author only knew that every parent had a child with Down syndrome, which meant that they were all addressed equally during the interviews.

Compared to other qualitative methods, such as using a questionnaire, there is no room for follow-up questions in case the information should be unclear (Granskär & Höglund-Nielsen, 2012). In this study follow-up questions were required, considering the mix of languages, for the result to be clearer and to avoid misunderstandings.

The interviewer must be alert to the given information to determine that it comes from the participant’s own observations, and not from a secondary source (Granskär & Höglund-Nielsen, 2012). The author took this into account during the transcriptions. By recording the interviews there was an opportunity to go back and go through the material several times, which was of great importance in avoiding errors, since there was different languages involved.

In the analysing process the author selected the most appropriate meaning units in relation to the aim. The author avoided using several paragraphs in one meaning unit since it would become difficult to manage. Some of the meaning units were of multiple meanings and to be able to create a proper code there was some degree of interpretation. During the condensation and abstraction the author was aware of the risks of losing meaning of the text. A comparison was made between the categories and the collected data to double-check that there wasn’t any relevant data that had been excluded. This was also to make
sure that no irrelevant data had been included. The author took in consideration the context of which the information had emerged, and thereafter named the code. By sorting the codes it created more specific categories, which in turn illuminated the core of the information received during the interviews. Example of meaning units, condensed meaning units and codes were not included, as it would have to be translated and not reproduce the exact analysis satisfactorily.

Qualitative studies have several strengths. This type of study is based on human experiences which in itself is powerful and may be more compelling than quantitative data (McMillan, 2009). Parents participated in this study represented a diverse selection group. In the interviews the author could guide the sequence of the interview questions the way it suited the responses of the informant. The interviews were recorded which gave the author a valid basis to analyse. The author had access to a proof reader which could give feedback on the free translations of the citations as well as during the analysing process.

The main weakness is that the study only has one writer, which limits the opportunities in variation of perspectives and discussion regarding the analysing process. This may have affected the outcome of the result. Furthermore it was the first time for the writer to do semi-structured interviews and according to McMillan (2009) it is important to have experience to not influence the quality of the study through personal idiosyncrasies and biases. A more experienced author may have composed the questions in a different way to receive more detailed and nuanced responds. Furthermore the conclusions drawn are limited to the participating parents and the author cannot assure that the same categories would be found with a different sample.

**Cultural aspects**

To conduct a study in a different country with another culture comes with both advantages and disadvantages. There is a whole set of new social rules and codes to relate to which is challenging in itself. At the same time it is a great opportunity to gain new experiences, learn and establish new contacts. Since the author had already been to Costa Rica, some experience had already been gained about the culture and the people. This time the aim of the stay was completely different, which required additional knowledge and reflection.

The plan was to send all the information to the principal already in the beginning of February, but the author’s contacts advised not to. According to them it would be considered impolite and it wouldn’t benefit the study since in Costa Rica it is the meeting between people that counts. The systems contain a lot of bureaucracy, especially regarding the school and education system, which isn’t always electronic. Things go slower and thereof the author had to be proactive in order to come in contact with the parents. To get permission from the principal was no major problem, but thereafter it was the author’s responsibility to make things happen. Simultaneously the author had to make a good impression and not be very straightforward but show respect. Some of these cultural aspects contributed to some frustration since they together with holidays limited the timeframe of conducting the interviews.

During the first two weeks different perspectives had been received regarding the Costa Ricans openness for this type of subject. Some had said that Costa Ricans are not very fond of sharing these things with strangers, while others had confirmed that they in fact are very open and happily talk about it. The author got the impression that everything concerning children in general is considered as delicate and sensitive. During the interviews the author
experienced a mix of the two sides, which can be seen looking at the differences in length of the interviews.

The thought was that the principal and/or other employees with authority at the school would be the ones who selected the parents. As mentioned under data collection the first two were selected with help from employees. Thereafter it seemed to be the author’s responsibility to continue, which in turn affected the method and some of the ethical aspects regarding the sampling.

Even if six interviews were sufficient in relation to the study’s dimension, the author would have wished to interview another father. Unfortunately the majority of the ones who were assumed to represent a father were either a brother or another male member in the family, and therefore they couldn’t participate. The majority of the ones who came to the school were women, which may be a reflection of the Costa Rican culture.

**Language and communication**

During the writing of this study there were three different languages involved: English, Spanish and Swedish. Due to this there have been frequent translations on-going, especially regarding the interviews and analysis of the transcriptions. There is a possibility that errors have occurred in the translation and interpretation of the transcriptions. To avoid this as much as possible the author enlisted the help of different dictionaries as well as a local proof reader. The proof reader contributed especially to the translation of the citations since they contained expressions typical for Costa Rica. The author was aware of that the proof reader could possibly influence the meaning of the citations. Therefore the translations were compared with the appurtenant interview text, to assure they were appropriate in relation to the context.

Using the knowledge retrieved from Alex Muigai, (SIDA Partnership Forum, 2014-03-12) the author paid extra attention to make sure that the participants’ narratives were understood. Through the follow-up questions the participants were able to develop their answer or confirm what they just said, which in turn highlighted the delivered message. During the transcriptions the author noted that follow-up questions would have been needed more frequently during the interviews, in order to get further explanations and/or more descriptive information from the informants. This was not done due to the somewhat limited vocabulary knowledge of the author, which may have affected the outcome of the result. Despite this fact the author felt that the collected data was sufficient to create a credible result.

**Conclusions**

The findings from this study illuminate the experiences of parents having a child with Down syndrome in Costa Rica. The result addresses various aspects of this phenomenon, some in general and some more specific. The informants answered the aim by accounting their personal experiences of how Costa Rica respond to needs and demands for their children in daily life. When comparing the result with previous research and other sources of information there were several similarities. Parents in Costa Rica tend to have the same kind of positive and negative experiences as parents elsewhere of children with Down syndrome. The findings suggest that Costa Rica is a country with deficiencies when it comes to the social, legal and educational system, which in turn affects the daily life of
these parents and their children. What was considered positive were the school as such and
the health care provided.

**Implications for future research**

Through this study other parents in similar situations may share, understand or gain new
perspectives by reading the citations. What can and/or may differ are the differences within
the countries and cultures, regarding knowledge, access of adequate support and education,
family situation and so forth. From these conclusions emerges the question of what further
research is necessary. This will be addressed here below.

This study is made near San José, the capital, which gives perspectives based on the
resources available in this specific area. It would have been of interest to compare these
with the experiences of parents in rural areas, in order to get a more varied perspective of
this phenomenon.

This study focus on experiences of parents having a child, aged between a few months to 9
years, with Down syndrome. The life expectancy of these individuals nowadays can be up
to 60 years old. With this come a new approach and a whole new set of expectations and
demands on parents, society and health care. It would be of interest to examine the lives of
adults with Down syndrome in Costa Rica, as a complement in order to get a wider
perspective of the situation of these individuals in this specific country.

Aside from covering the age span it would be of interest to investigate more about the
health care of these individuals. The author suggests further research surrounding health
care workers attitudes and experiences of meeting these individuals in their profession. Do
they feel they have enough knowledge to provide professional and adequate care for
individuals with Down syndrome? Experiences of both parents and health care workers
could be able to bring more knowledge and information, which may contribute to a higher
quality of health care in general.

**Clinical relevance**

This study is mainly directed to the Costa Rican population and government. It highlights
the voice of this specific group of parents and points at things that has to change and can be
changed. It contributes to the knowledge of Down syndrome as well as evokes the idea
surrounding the knowledge of other intellectual disabilities.

Since Down syndrome is the most common chromosomal disorder and these individuals
often need health care, it’s most likely to meet one of these individuals during a career as a
nurse. This study may arise the awareness of this diagnosis in health care workers and the
knowledge may benefit the quality of health care of these individuals as well as it benefits
the interaction with the parents. Additionally, it may benefit health care workers as it gives
a Costa Rican perspective, which can be of use since health care is becoming more
multicultural.

As a student from abroad highlighting this problem area in, it may have a small impact or
give some confidence to the people working to improve the current situation.
REFERENCES


Asociación Síndrome de Down Costa Rica (ASIDOWN) Seen: 2014-03-18 at 15.00 http://asidown.org


Federación Iberoamericana de Síndrome de Down (FIADOWN) Seen: 2014-03-18 at 15.45 http://www.fiadown.org/content/fiadown

Seen: 2014-03-27 at 14.00
http://www.disabilityworld.org/07-08_01/spanish/ninos/derechos.shtml


Global Down Syndrome Foundation
Seen: 2014-04-02 at. 15.35.


National Down Syndrome Society (NDSS)
See: 2014-03-29 at 16.10


O'Neill, O. (2003). Symposium on consent and confidentiality - Some limits of informed consent. *Journal of Medical Ethics, 29*, 4-7. doi:10.1136/jme.29.1.4


World Down Syndrome Day (WDSD)
Seen: 2014-03-18 at 14.50
http://www.worlddownsyndromeday.org/about-wdsd
APPENDIX A

Interview guide

- Tell me something positive about your son/daughter.
- Would you like to share some of your experiences of daily life with a son/daughter with Down syndrome?
- Can you tell me about a typical day for you, from when you get up until you go to bed?
- Would you like to tell me about the daily activities of the family?
- What kind of resources, both inner and outer, do you and your family have or count with?
- Do you know any other family that also have a child with Down syndrome?
- (If yes): Do you share your experiences with each other?
- Is there anything you would like to change?
- Do you have anything more to add that would be important for you or your son/daughter?

Follow-up questions

- Would you please tell me little bit more?
- In what way…?
- Can you be a little more specific, please?
- Would you please give me an example?

Translated in Spanish:

Preguntas para la entrevista

- Cuéntame algo positivo de su hijo/hijo.
- ¿Quieres contarme sobre sus experiencias de su vida cotidiana con un hijo / una hija con síndrome de Down?
- ¿Puedes contarme sobre un día normal para usted, desde que se levanta hasta que va/van a dormir?
- ¿Quieres decirme sobre las actividades diarias de ustedes?
- ¿Con que tipo de recursos propios, familiares o algún otro cuenta la familia/ustedes?
- ¿Usted conoce otras familias que tiene un hijo/una hija con síndrome de Down?
- (Si sí): ¿Comparten sus experiencias entre familias?
- ¿Hay algo que le gustaría cambiar?
- ¿Tiene algo más que quiere agregar que sea importante para usted/el niño?

Preguntas complementarias:

- Puede hablarme un poco más/algo más, por favor?
- En qué manera…?
- Puede especificar, por favor?
- Puede darme un ejemplo, por favor?
APPENDIX B

Distinguida Señora Directora,

Me llamo Stina Persson y escribo en referencia a hacer una presentación de mi y de mi proyecto. Soy una estudiante de enfermería del colegio Sophiahemmet Högskola en Estocolmo, Suecia. Ahora estoy estudiando el tercero y último año. Una parte de la examinación es escribir un tesis y tengo la oportunidad de escribirlo en otro país. Se llama “Minor Field Study” (estudio de campo de menor envergadura) gestionado por The Swedish Council for Higher Education y financiado por Asdi, la Agencia Sueca de Desarrollo Internacional.

La etiología y patología de síndrome de Down no es completa a pesar del mayor conocimiento genético. Hoy los niños con síndrome de Down viven con su familia y son más integrados en la sociedad. Estos son dos de muchos razones porque es necesario que la investigación continúe.

El sujeto que será estudiado es las experiencias de padres que tienen hijos con síndrome de Down. Por eso estoy interesada de hacer entrevistas con padres que cumplen con estos criterios:
- Que es padre de un hijo que tiene síndrome de Down.
- Que el hijo será entre las edades 6 y 10.
- Que la familia vive cerca de San José, la capital de Costa Rica.

El objetivo del tesis es describir las experiencias de los padres de la vida cotidiana con hijos con síndrome de Down en Costa Rica. A usar entrevistas es un método cualitativo. Me he profundizado en investigación y literatura sobre síndrome de Down y el país Costa Rica.

Las entrevistas serán basados a preguntas narrativas y cerradas. Los participantes eligen el lugar para la entrevista. Las entrevistas serán grabadas y transcritas. A participar es totalmente voluntario, significa que tienen derecho de terminar cuando quieran. Nombres y otra información personal no serán disponibles para alguien mas que yo. Las entrevistas serán en español pero la composición será escrito en inglés.

Para el tesis necesito por mínimo ocho entrevistas. Ellos van a recibir una carta dónde hago la misma presentación y explico todo el proyecto y los derechos que tienen si deciden a participar. Le agradecería enormemente si pudiera hablar con varios padres y darles mis cartas, que para al final resulte en lo mínimo ocho entrevistas. Es importante que les doy tiempo para pensar si quieran participar o no.

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Atentamente
Stina Persson
APPENDIX C

Distinguidos Señores

Me llamo Stina Persson y esto es una presentación de mi proyecto. Soy una estudiante de enfermería del colegio Sophiahemmet Högskola en Estocolmo, Suecia. Ahora estoy estudiando el tercero y último año. Una parte de la examinación es escribir una tesis y tengo la oportunidad de hacerlo en otro país. Se llama “Minor Field Study” (estudio de campo de menor envergadura) gestionado por The Swedish Council for Higher Education y financiado por Asdi, la Agencia Sueca de Desarrollo Internacional.

La etiología y patología de síndrome de Down no es completa a pesar del mayor conocimiento genético. Hoy los niños con síndrome de Down viven con su familia y son mas integrados en la sociedad. Costa Rica es un país que ha tenido un desarrollo muy fuerte durante los últimos años. Por eso es interesante para mi ver como es tener un hijo con síndrome de Down en Costa Rica.

El objetivo es describir las experiencias de los padres de la vida cotidiana con hijos con síndrome de Down. Por eso estoy interesada de hacer entrevistas con padres que cumplen con estos criterios:

- Que es ser padre de un hijo que tiene síndrome de Down.
- Que el hijo será entre las edades 1 y 18.
- Que la familia vive cerca de San José, la capital de Costa Rica.

El usar entrevistas es un método cualitativo, me he profundizado en investigación y literatura sobre síndrome de Down y el país Costa Rica.

Las entrevistas serán basados en preguntas narrativas y cerradas. Son destinadas a responder el objetivo de la tesis. Los participantes elijen el lugar para la entrevista. Las entrevistas serán grabadas y transcritas. Participar es totalmente voluntario, significa que tienen derecho de terminar cuando quieran. Nombres y otra información personal no serán disponibles para alguien mas que yo. Las entrevistas serán en español pero la tesis será escrito en inglés.

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