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Journal of Pediatric Nursing

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Citation for the published paper:

Trollvik, A., & Nordbach, R. (2011). Children's Experiences of Living With Asthma: Fear of Exacerbations and Being Ostracized. *Journal of Pediatric Nursing : Nursing Care of Children and Families*, 26(4), 295-303

DOI: 10.1016/j.pedn.2010.05.003

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Abstract

The aim was to explore children's experiences of asthma in order to tailor a learning program based on their perspectives. Fifteen children (7 -10 yrs) were interviewed and they narrated about their drawings; a phenomenological and hermeneutical approach was used in the analysis. The findings are described in two themes with five subthemes: fear of exacerbation (bodily sensations, frightening experiences, loss of control) and fear of being ostracized (experiences of being excluded, dilemma of keeping the asthma secret or being open about). Drawings, as applied in the present study, are a good tool for initiating a dialogue with children.

Key words: Child health, asthma, drawings, qualitative research, health promotion

Children's experiences of living with asthma: Fear of exacerbations and being ostracized

Living with a chronic disease often affects a child's whole life, psychologically, physically, socially and spiritually. Darbyshire, MacDougall, & Schiller (2005) highlight the importance of children influencing services and facilities that are provided for them. The Convention on the Rights of the Child (Unicef, 2008) enshrines children's rights to participate and to express their views freely in all matters. The patient's rights act (1999) stresses that information must be adapted to the qualifications of the individual recipient, i.e., age maturity, experience, cultural and linguistic background. Thus, when planning learning programmes and approaching children, we have to explore children's experiences and needs so that new programmes are optimally tailored to the target group.

BACKGROUND

Asthma is the most common childhood disease and long-term medical condition affecting children (Masoli, Fabian, Holt, Beasley, & Global Initiative for Asthma (GINA) Program, 2004). The prevalence of asthma is increasing and atopic diseases are considered to be a worldwide health problem and an agent of morbidity in children (Masoli et al., 2004). A Norwegian cohort study among 10-year old children concluded that lifetime prevalence of asthma was 20.2%, current asthma was 11.1% and doctor diagnosis of asthma was 16.1%, the highest number ever reported in Scandinavia, boys are more affected than girls (Carlsen et al., 2006). A Nordic study of children aged 2-17 years found that asthma, allergies and eczema were the most commonly reported long-term illnesses (Berntsson, 2000). Many children and their families are thus affected by asthma directly or indirectly.

Rydström, Englund, & Sandman (1999) found that children with asthma show signs of uncertainty, guilt and fear and feel like outsiders in everyday life. Studies show that children with asthma have more emotional/behavioural problems than healthy children (Reichenberg

& Broberg, 2004). Chiang, Huang, & Fu (2006) observed that children with asthma, especially girls, participate less in physical activity. It has also been found that asthma control in children is poor and that health care professionals (HCP) and children focus on different aspects of having asthma (Price et al., 2002); HCP's focus on symptoms whilst children focus on activity limitations. Guyatt, Juniper, Griffith, Feeny, & Ferrie (1997) stated that children as young as 7 years old are able to accurately report changes in symptoms for periods as long as one month. These studies however are mainly from a caregiver's perspective than from the perspective of the child's own experience. Few studies have considered very young children's, 7-10 years old, perspectives; this study might contribute to new insights into their life-world experiences. The aim of the study was to explore and describe children's everyday experiences of living with asthma in order to tailor an asthma education programme based on their perspectives.

METHODS

Design

A qualitative approach was chosen in order to acquire a deeper understanding of how children experience asthma in their daily life and to obtain a view of their thoughts and meanings (Kvale, 1997). Data have been collected by means of interviews and drawings. Phenomenology, as created by Husserl and further developed by Merleau-Ponty (2004), focuses on people's *life-world* as they experience it. The life-world perspective goes back to the things themselves, i.e., experience is considered to be an individual's perception of his or her presence in the world. The life-world is unique for every person, but shared with others and can be seen as an inter-subjective dimension of the life-world (Merleau-Ponty, 2004, Dahlberg & Dahlberg, 2004).

In the present study, a phenomenological and hermeneutical approach was used to gain an understanding of the children's life-world and Epoché was used to try to approach the phenomenon described as openly and naïvely as possible (Kvale, 1997; Hummelvoll & Barbosa da Silva, 1998). The four authors all had a pre-knowledge that influenced the interpretation of the findings; AT and RN, both nurses specialised in asthma, have worked clinically with children with asthma and education, KCR has worked with adult patients with asthma and CS has worked with adults and education.

Subjects

Fifteen children were strategically selected with regard to age, 7-10 yrs, boys and girls and severity of asthma, moderate and severe, by a nurse specialised in asthma. They spoke and understood Norwegian, had normal cognitive development and, prior to the interview, had not participated in an Asthma Education Program (AEP). The selection was made among the children, who had consecutively visited a paediatric ward in 2005/2006. Nine boys and six girls, all had allergies, although this was not an inclusion criterion, participated in the study. After having interviewed 15 children, their narratives became repetitive. Background information was given by the parents, (see table 1); In 12 families, the parents were married, 3 were not. 12 families lived in rural areas and 3 did not. After the interview, the parents of two of the children stated that even if the children had moderate to severe asthma, they did not take their medication daily.

Procedure

Fourteen children were interviewed at the hospital or in a café and one at home. The parents were not present. The first two children were interviewed together because initially it was planned to collect data by means of focus groups. This was changed because it was difficult for the children to meet up at the same time for the interview. The interviews lasted 30 – 60 minutes, were audio-taped and transcribed verbatim. They were conducted by two of

the authors (AT, RN), with the exception of one conducted by AT. The interviews were semi-structured, open and conversational in style. An interview guide was used with the following topics: 1) experiences of asthma in daily life, physical as well as mental/psychological; at home, during leisure time and at school, 2) feelings, bodily sensations and verbal expressions of asthma, 3) communication about asthma with teachers and peers. The children were also free to spell out other thoughts and experiences during the interviews, but the main focus was on experiences in relation to having asthma. Towards the end of the interview, a meta-communication technique was used to help the children to express themselves further and for a inter-subjective validation (Kvale 1997); one of the interviewers made a drawing of a boy-girl and asked some of the interviewee questions again to confirm that they had understood what the child had meant in the dialogue. At the end of the interview all the children, except one, made a drawing of a situation they had described in the interview. The children explained the meaning behind their finished drawings (Driessnack, 2005).

The Norwegian Regional Ethics Committee has approved the study (953/05). A nurse specialised in asthma (RN) asked the parents if they wanted their child to participate in the study. The researcher (AT) informed the family about the study, and then *both* the parents and the child gave their informed written consent before being interviewed. All information was treated confidentially.

Data analyses

The interviews were listened to, transcribed, read several times and keywords were written in the margins of the manuscript. A preliminary analysis was performed after four interviews, followed by the main analysis on three levels: 1) Self-understanding. A concrete phenomenological description of the phenomena was made. 2) Reading the interviews several times to achieve a sense of the whole: Commonsense understanding level, which means acquiring a broader context of knowledge. The investigator read the text to understand how

the children reported the phenomenon. The different themes were identified and transformed into meaning units and then coded into themes and subthemes (see table 2). 3) Theoretical understanding, which emphasizes the hermeneutical deep understanding and meaning, with the use of the hermeneutic circle, was used (Kvale, 1997; Hummelvoll and Barbosa da Siva, 1998).

To achieve trustworthiness (Patton, 2002) data were collected by means of interviews and drawings and their findings were triangulated. The two authors who performed the interviews discussed them afterwards. All the authors have continuously discussed the analysis of the findings. The analysis method is described thoroughly and quotations presented are intended to facilitate the reader's evaluation of the trustworthiness of the findings. To obtain inter-subjective validation (Kvale, 1997); simple language, drawings and meta-communication were used to ensure mutual understanding with the child.

RESULTS

The findings are described in two themes with five attendant subthemes relating to the main themes covered in the interviews; *fear of exacerbation* and *fear of being ostracized*. The subthemes include different aspects of the themes (see table 3). The themes are also illustrated with six drawings made by the children (see figure I-VI).

Fear of exacerbation

The children described loss of control in concrete situations in life and said that they feared the onset of exacerbation and that they were worried about getting breathing problems and how asthma affected their body.

Bodily sensations

The children used many different words when they described how asthma affected them and there was no common word for their descriptions, "...I can't breath... difficult to breathe... have asthma...tired...exhausted...can't laugh or talk...breathe heavily...tight in my

chest...sore in my throat...sound in my throat...my throat is strangled...something in my throat...can't swallow....”

The children referred to physical changes in their body before the actual physical sensation of asthma; the heart beating faster, heavy breathing and the throat feeling strangled. A boy described how he felt it in his body, “...it's bad having it (asthma), I like physical activity, but I often need to stop; it hurts in my body, my breathing gets heavy, my heart starts to bump quicker and then, then, you get warm in your head, you get tight in your chest, you breathe in very heavily, you almost faint....”

One boy described how an allergic reaction could affect his body, how his eyes became swollen and how his appearance could change, “...I can feel it if I am close to a horse or a dog; my eyes start to itch and then they become red and swollen and very nasty. I look really flabby and disgusting even though I'm actually not....”

When asked where asthma is located in the body, most of the children pointed at the throat, but some pointed towards their lungs and stomach. They explained that the lungs were small and were situated near the throat, “...asthma – it feels like a big bubble in my throat that can't burst....”

One girl said that there is a difference in being “asthma-tired” and “only tired”. When she was cycling she sometimes got asthma-tired and then she felt, “...tight in her chest....” (she pointed at her chest), if she was only tired she was only, “...tired in her feet....”

Frightening experiences

The children described frightening experiences of asthma and allergy as the worst thing they have ever experienced, as this boy expressed “...oh, I had never experienced anything worse than when my lips got gigantic and swollen, they got so swollen and my eyes almost disappeared, they were red and very, very tight, I've never experienced anything worse than that....”

A girl said that she was frightened at night, "...the worst day of my life was the very first day I was aware of my terrible asthma. I was frightened, it was in the evening or in the night...."

Figure I

A boy allergic to dogs told a story about when he was visiting his aunt and that she had a dog at home. He woke up at night with a tightness in his chest. His aunt gave him medicine to inhale, which improved his breathing. The drawing shows the dog that caused the breathing problem and the boy inhaling medicine from the mask.

Figure II

One girl suffered from an acute attack of asthma. She described how her father drove very fast to the hospital and she was afraid that the police were going to stop the car. The drawing shows her sitting in the car passing the police station.

Loss of control

The children often referred to situations in the dark and at night when they felt that they had lost control. One boy said that when he was tired at night and it was difficult to breathe properly because of asthma, he fell asleep very late. He woke up during the night with feelings of tightness in his chest and felt frightened. A boy expressed another way of losing control, "...you have to constrict all your muscles and you need to rest, you need to use all your energy and you need to rest...." and he continued by saying that asthma is almost impossible for others, who do not suffer from asthma, to understand.

The children described how their condition changed from day to day, and even from one hour to the next, and that they felt that they had no control. The participants experienced that they were able to both participate and not participate in activities during the same day due to sudden changes in their condition. They also said that they could play at school normally, but when they reached home and could relax they felt exhausted. One boy described it like this:

"...just before it happens (asthma) I'm having fun and running around, one second later I'm lying on the ground because all the energy is empty in my body and I need to rest, my whole body is weak...."

Another boy described how quickly his condition could change in one day, "...the worst thing I have experienced was when my throat was so strangled that I felt that my airways were narrower. It started by having a sore throat when I left school and suddenly it was tight in my chest. It continued for a week...."

Figure III

A boy allergic to dogs used to walk with his neighbour's dog, he told how the dog ran so fast that he could almost not keep up. However, he had to follow the dog and started to run and got breathing problems. The drawing shows that instead of the boy walking the dog, the dog was walking him.

Fear of being ostracized

The fear of being ostracized concerned all aspects of the child's life and they related the dilemma of keeping the asthma secret or being open about it and the negative experiences of being excluded from games and many other activities that children regularly participate in.

Experiences of being excluded

The main reason expressed for being ostracized was physical activity such as playing, running, football, handball, skiing and jumping. Another reason was allergy such as allergy to pets and food. One girl said that she was excluded from doing fun things and that her friends got bored waiting for her, "...I can't participate in the things like handball, football and so on. I've been using medication for a long time and sometimes my friends get bored waiting for me because I can't play and jump so much...."

A boy said that he thought his friends knew he was using medicine for asthma, but they often chose to ignore the fact. When he and his friend were out running, they often ignored his

condition and he felt that they did not respect him. They wanted him to run, even though they knew that he could not manage to run like them and that he would then get very tired. When he asked them to take a rest they refused and he felt forced to continue even though he knew that his asthma could get worse.

During the interviews, the children explained that peers and teachers sometimes seemed to forget about the asthma or the allergy. This caused problems when the child was visiting relatives and friends, as many families have house pets. Going to birthday parties or being close to peers in the classroom who had animals at home could result in breathing problems. One boy said that in his class only four pupils did not have an animal and that his two best friends had animals at home. He felt excluded when the class went on farm visits and he could not participate because of his allergic reaction. One boy said: "...the worst time at school is the free time, because we have to run and play all the time...."

A girl related that when the weather was cold and the rest of the class were outside playing or having lessons, she had to stay inside because the cold air caused breathing problems. A boy said that he was served certain food at school, but he could not eat it because of his allergic reaction, "...I can tell you something that is sad for me at school and is difficult for me to explain; when we are served cakes at school, it's no fun for me; I can't eat the cake because I am allergic to milk. So I leave the room without a cake in my hand...."

Figure IV

A girl said that while she was playing with three friends she got tired, she could not run as fast as the others and they had left her. The drawing shows that she is waving to them as she cannot keep up with them.

Figure V

A girl said that she went for a cycle ride with friends. She was the last one to cycle up a hill due to exhaustion brought on by asthma. She said that she could not breathe properly and she had to stop cycling. The drawing shows how the others disappeared uphill.

Dilemma - keeping the asthma secret or being open about it

The children were eager to participate in social and physical activities and tried not to be regarded as different. They described how they felt that asthma was visible only to them and not to others and that they were worried about getting breathing problems. The participants described feelings of loneliness when living with asthma. During their attempts to participate in activities, they were reluctant to tell others, friends, schoolmates and their teachers about their asthma and their experiences of living with the condition. The decision whether to tell this "secret" or not was expressed as a real dilemma. Some of the children said that they might tell their closest friend, but others did not want anybody to know about it for fear of being teased, as a girl put it: "...I don't dare tell the others about having asthma. There are so many noisy boys in my class, suddenly they start shouting and ask and ask and ask...."

Some of the children said that they thought that other children did not know about their asthma and that they did not know if the teacher had been informed about it. The children themselves did not tell other members of the class about the asthma and they often did not know if anybody else had the same disease. A boy said that he was embarrassed by his schoolmates because he could not accompany them in activities, "...when I'm at school they embarrass me so much that I don't want to be there any longer...."

Some children described how they chose to tell others that they were exhausted and stopped the activity and therefore voluntarily excluded themselves. Sometimes the children continued their activities and took the risk of being exhausted. It was more common that the boys said that they chose to continue the activity while the girls said that they stopped earlier and preferred less strenuous activities. The children felt that they controlled the situation by

not telling and just pretending that everything was normal, as one girl put it: ...” sometimes I pretend I’m just an ordinary person, but not always...”

Not many of the children were open about having asthma, but some of them said that they could ask others, children or adults, for help when suffering from an asthma attack. A boy said that on one occasion when he laid on the ground breathing heavily, the other children helped him and asked him how he was because they knew about the asthma.

Figure VI

One boy often got exhausted when playing ice hockey. He felt he had to rest and sat down for a while. He then went back to play with the others. This boy had openly informed his teacher about the asthma and he felt that the teacher supported him when necessary. The teacher made sure he was participating in the activity. The drawing shows him – the smiling boy in blue - close to the teacher playing ice hockey.

DISCUSSION

In this study, children described in their own words and from their perspective what it is like living with asthma. The drawings made by the children and their explanations provided a deeper understanding of their life-world and their inner thoughts. The findings reveal their fear of bodily sensations of exacerbation as well as their fear of being ostracized. The fear of being isolated and different from others sometimes forced the children to participate in activities causing breathlessness or to make the choice to be excluded. They suffered in silence and it is obvious that people in the environment need a better understanding of the children's situation and dilemmas.

The children described loss of control over their body and its reactions. The sudden changes made it difficult for them to be able to trust their body and its reactions. They did not regularly express their feelings to others. Merleau-Ponty (2004) claims that the body is a premise for human life and that each person has his-her own experience and knowledge that is

close to the body reactions. This experience is perceived within the body and he named it *the embodied knowledge*. According to this theory, the children need to further develop their body knowledge and learn to trust their bodily reactions, to verbalise the illness and find methods to be aware of it in order to be capable of coping with their condition. The children related how they felt asthma in their body and they described it in different ways and with different words. The children in this present study, like the children in Woodgate's (2009) study, used a multitude of words to describe asthma. Asthma is classified as *one* disease, although it appears differently in different persons. This might be difficult for others to understand and lead to misunderstanding. The changing symptoms over time might also be difficult to understand for both the child itself and people around him-her.

The children expressed that they were caught in a dilemma of either keeping the asthma secret or revealing it. They were reluctant to tell others, friends, schoolmates and teachers, about their asthma as they were afraid of not being accepted and being labeled as *different* by their peers and, as a consequence, being ostracized. The fear of being excluded and being labeled as an outsider is also found in other studies of children with chronic diseases (Rydström et al., 1999; Sällfors, Hallberg, & Fasth, 2001). Many of the children did not know other children with asthma, which indicates that it is common that children hide their symptoms and breathing problems in view of the fact that the prevalence of current asthma is so high 11.1% (Carlsen et al., 2006). McCann et al., (2002) also indicated that teachers underestimate asthma prevalence in schools. The findings show that the children felt that HCPs, teachers and parents did not talk with them about fear, anxiousness and loneliness. One reason for this might be that the adults are afraid of placing a burden on the child by asking serious questions. Another reason could be that HCPs, teachers and parents may regard asthma as solely a medical condition, without any psychological influence. This might result in children being neglected psychosocially. They might not be aware that children also have a

need and the ability to talk about psychological matters in relation to a chronic disease so they can learn about their reactions and develop appropriate coping strategies for use in daily life.

The boys described that they continued physical activities more often while the girls stopped earlier. The findings show that there are indications that some of the children were under-medicated and did not use medication correctly. Some children, especially the boys, forgot to take their medication and both boys and girls hid when inhaling drugs. This gender imbalance is also seen in a study of adolescents by Williams (2000) who found that girls incorporate chronic illness more into social settings and medicate themselves in public settings, while boys participated more in sporting activities and seemed less willing to take prescribed medication.

The children in this study did not mention the public health nurse as a resource as did the children in a Swedish study (Rydstrom et al., 1999). Canham et al., (2007) stated that one in four children took sole responsibility for their medication and mentioned the school nurse as a resource as she has knowledge and expertise. Thus, there seems to be a gap between the children's need of care and the HCP support of teachers and children concerning knowledge, care and follow-up. The children described how they strived to participate in the other children's activities and be like the others without thinking about the consequences of the illness. It seems as if they live more with a health focus than a disease focus meaning that they have a salutogenic perspective (Antonovsky, 1996). The salutogenic (salus = health) approach focuses on resources for health rather than the risk of diseases. Health is thus seen as a movement in a continuum between total ill-health (dis-ease) and total health (ease) (Antonovsky, 1996).

Strengths and weaknesses of the study

The strength of the study is that it takes the children's life-world as its starting point. However, one weakness is that few episodes are described from a home environment

perspective. This could be due to the fact that the interviewers did not focus sufficiently on the home environment or that school and leisure time caused them more problems. Another strength is the use of different strategies and methods to involve the children by providing them with an opportunity to give their views (Kirk, 2007) and that the researcher group was aware of the children's age, development stage and the influence that an adult researcher can exert over the child (Christensen & James, 2008). In a statistical sense, as the selection of informants was strategic, the findings cannot be generalised to a broader population but may serve as an "eye opener" that helps to generate new hypotheses and ideas about how children experience living with asthma in daily life.

Relevance to clinical practice

The study could contribute to new insights into children's perspectives of their illness and thus make it possible to tailor an AEP based on their needs. Using drawings, as in the present study, is a good tool for initiating a dialogue and gaining access to young children's inner thoughts. Future asthma education and learning programs should be developed *together* with children and be based on *their* needs. Before the group sessions, each child should be interviewed individually. This first narrative could be the gate opener for the rest of the learning programme; the child's psychological feelings will be detected and topics important to the child as well as each child's level of understanding will emerge. There should be a focus on a salutogenic perspective building on the child's own health focus. AEP for parents (Trollvik & Severinsson, 2005) should be provided with a special emphasis on encouraging the parents to be open to the child's feelings about and expressions of asthma. Further, the parents should be motivated to inform the teacher and the classmates, if the child so wishes, a process HCPs should have a responsibility to assist and support.

Conclusion

Asthma management is a major issue for children but also for HCPs, teachers and parents. This study clearly shows that there is a risk that a child suffering from asthma feels lonely and isolated and that this feeling of isolation might be detrimental to the child's physical and psychosocial development. The children's descriptions can contribute to an increase in HCPs', teachers' and parents' understanding of the children and they should have a cooperative responsibility for the children in school. HCPs such as school nurses or public health nurses should be more active in school and be a professional resource for teachers in order to strengthen their competence in assisting children with asthma. A health promotion strategy (Rootman, Goodstadt, Hyndman, McQueen, Potvin, & Springett, 2001) would be to work both individually and intersectionally with a multi-strategic approach so that the families are given a sustainable follow-up. Written guidelines and responsibility clarifications should be formulated with the active participation of children and their parents. In a future study, it might be fruitful to focus more on salutogenic factors when interviewing children.

ACKNOWLEDGEMENT

The authors want to especially thank the children for participating in this study. Hedmark University College, Innlandet Hospital Trust and Nordic School of Public Health have founded the study. No other commercial funding is involved.

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Table 1 Background data of interviewed children.

Note: B: boys G: girls MA: moderate asthma SA: severe asthma A: animals P: pollen F: food

M: house dust mite Y: yes N: no.

No	Age	Gen der	Severity of asthma	Daily medi- cation	Type of allergy	Duration of asthma (years)	No. of siblings	Heredity
1	9	G	MA	Y	A	5	3	Y
2	7	B	SA	Y	A	3	2	Y
3	10	B	SA	Y	A	5	2	Y
4	8	G	MA	Y	P	2	1	Y
5	10	G	MA	N	A	1	3	Y
6	9	B	MA	N	A	7	2	Y
7	9	B	MA	Y	A P	3	2	N
8	9	G	MA	Y	A	3	2	Y
9	10	B	MA	Y	P	3	1	N
10	8	B	MA	Y	A P	5	3	Y
11	9	B	MA	Y	A F	1	0	Y
12	8	B	MA	Y	F	7	1	Y
13	10	G	MA	Y	APF	2	1	Y
14	7	B	MA	Y	A F	1	1	Y
15	9	G	MA	Y	M	1	1	Y

Table 2 Example of data analysis level 2

Meaning unit	Code	Subtheme	Theme
"... sometimes I pretend I'm just an ordinary person, but not always...."	Feeling of not being like all the others and hide it	Dilemma of keeping the asthma secret or being open about it	Fear of being ostracized

Table 3 Themes, Subthemes, and Drawings

Theme: Walking a tightrope between keeping the asthma a secret or being open about it		
Theme	Subtheme	Drawing
Fear of exacerbation	Bodily sensations	
	Frightening experiences	Drawing 1, 2
	Loss of control	Drawing 3
Fear of being ostracized	Experiences of being excluded	Drawing 4, 5
	Dilemma of keeping the asthma secret or being open about it	Drawing 6

Figure 1

DOG

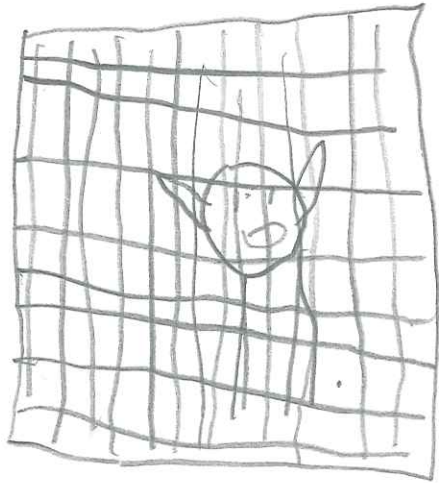


Figure II



Figure III



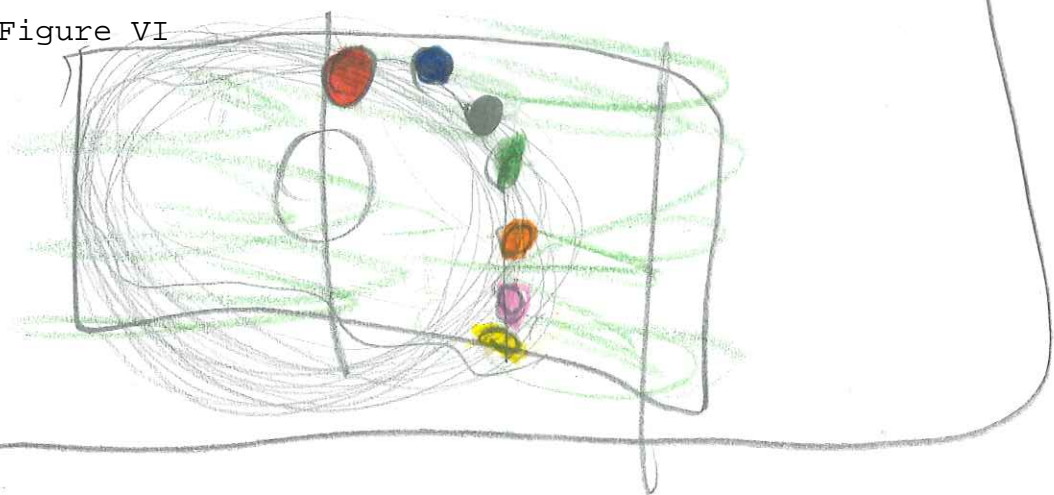
Figure IV



Figure V



Figure VI



1 2 3 4 5

1 2 3 4 5

