

Stimulating adherence through pictorial medicine instructions

A study on how caregivers administer Amoxicillin syrup to treat childhood pneumonia, reasons for why they give it this way and the influence of pictorial medicine instructions on this in Kisumu, Kenya



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Abstract

Non-adherence to antibiotic is a major public health problem. Previous studies found that understanding and adherence to antibiotic instructions increased when the oral instructions from the pharmacists were supported by pictorial medicine instructions. However, due to their design it remains unclear for what reason adherence and understanding increased. Therefore, this study aimed to explore (1) how caregivers give an antibiotic treatment, (2) for what reason caregivers give treatment this way, and (3) if including pictorial medicine instructions have an influence on this and if so in what way.

Pictorial medicine instructions for Amoxicillin syrup were developed and pretested in Kilifi and Kisumu, Kenya. These pictorial instructions were given together with the Amoxicillin syrup to caregivers whose child was diagnosed with pneumonia at the pharmacies of two different public clinics in Kisumu. A qualitative study using semi-structured in-depth interviews with 27 respondents, structured observations and focus group discussions were conducted over a period of two months.

It was found that half of the caregivers used the pictorial instructions when administering the Amoxicillin syrup and the other half did not use these instructions. Pharmacists provide incomplete treatment instructions, and caregivers use past experiences and their perceptions and understandings of the disease and treatment to fill in the gaps. For caregivers who used the pictorial instructions, these instructions reinforced the oral instructions, past experience and their perceptions and they almost all of them gave the medicine correctly. Caregivers who did not read the pictorial instructions had no such reinforcement and all of them gave the medicine incorrectly. Furthermore, the findings indicate that awareness of the importance to complete a treatment course was a motivating factor for caregivers to follow treatment instructions.

The findings suggest that pictorial medicine instructions that contain an explanation for why to adhere could be a low cost intervention to increase adherence to Amoxicillin syrup to treat childhood pneumonia in Kenya.

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Abbreviations and terms used

ARV	Anti-retroviral therapy to treat HIV infection
CIOMS	The Council for International Organizations of Medical Sciences
DMoH	District Minister of Health
HSM	Heuristic-Systematic Model of Information Processing
KCR	KEMRI community representative
KEMRI	The Kenya Medical Research Institute
KNH/UoN-ERC	Kenyatta Hospital and University of Nairobi Ethical Research Committee
NCST	National Council of Science and Technology
NSD	Norwegian Social Science Data Service
MoH	Ministry of Health
PATH	Program for Appropriate Technology in Health
REK	Norwegian Research Ethics Committee
STC	Systematic text condensation
UNICEF	United Nations Children's Fund
WHO	World Health Organization

The following terms are used regularly in this thesis. The terms are defined on how they are most appropriate within this study and are based on a combination of dictionaries, research articles and guidelines.

Treatment dose	The amount of medicine required each time the medicine is administered to produce the desired effect
Treatment regime	A treatment plan that specifies the dosage and schedule of treatment
Treatment course	A period of continuous treatment with a drug
Pictogram	A drawing or a picture representing a word, idea or message
Pictorial materials	Any material that contains pictograms such as books, articles or information brochures

Pictorial instructions	A medicine instruction leaflet that contains pictograms, in this thesis also referred to as pictorial medicine instructions or pictorials
Literal interpretation	How a respondent interprets each separate object in the pictogram (Recognition, familiarity and acceptability of the separate objects)
Interpretation of meaning	How a respondent grasps and understands the intended messages in pictorial materials
Operational use	How pictorial materials will be used to carry out the intended instructions by their potential users

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1. Introduction

Non-adherence to antibiotic instructions is a global public health problem (Davey & Hayes, 2002; Holloway & Dijk van, 2011; Pechere, Hughes, Kardas, & Cornaglia, 2007; World Economic Forum, 2013). It can lead to rapidly increasing antimicrobial resistance (Holloway & Dijk van, 2011; World Economic Forum, 2013), and also to treatment failures with mortality as a result (Ayieko & English, 2007). According to World Health Organization (WHO) patient non-adherence to antibiotic treatment instructions is up to 50% worldwide (Holloway & Dijk van, 2011). However, these numbers can vary widely across different settings.

Dowse and Ehlers (2005) define adherence as “the extent to which a patient’s medication-taking behaviour corresponds with agreed recommendation from a health care provider”. There are several more definitions in the literature of this study subject and they all have in common that the patient is the decision maker on how to take the medication.

Several interventions have approached the adherence issue (Krueger, Felkey, & Berger, 2003). Providing pictorial medicine instructions with the medicine is an intervention that seems to be successful to increase adherence in a low literate audience. This means that the written medicine instructions include pictograms that could help patients or caregivers in giving a medicine according to these instructions. There are some studies that have shown that pictorial medicine instructions accompanied with oral instructions increases understanding and adherence to the treatment instructions (Dowse & Ehlers, 2005; Ngoh & Shepherd, 1997; Yin et al., 2008). However, it is questionable how realistic pictorial based counselling is in settings where communication between health providers and patients can be poor. Furthermore, due to the quantitative design of the previous studies they do not provide any insight concerning the way and reason the pictorial instructions increased understanding and adherence to the instructions.

Therefore, the aim of this project was to explore how caregivers gave an antibiotic treatment to their children, for what reason they gave it that way, and whether

including pictorial medicine instructions would have an influence on this and if so in what way.

The fieldwork was conducted in Kisumu district, Kenya. At the beginning of the fieldwork pictorial medicine instructions were developed and pretested for Amoxicillin syrup, the medicine used in the clinics to treat non-severe childhood pneumonia. During fieldwork the pharmacists at two different public clinics provided the pictorial instructions with the Amoxicillin syrup when a child was diagnosed with pneumonia. We then interviewed the caregiver of the child in their home five to seven days after the clinic visit, to assess how they administered the Amoxicillin syrup, for what reason they gave it this way, and if and how the pictorial instructions had an influence on this. The study had a qualitative research design, using observations, semi-structured interviews and focus group discussions with the purpose of gaining insight into the aims of this study.

1.1 Thesis structure

Chapter two presents the literature review. It describes current knowledge about the factors that influence patients' adherence to antibiotic instructions, and pictorial medicine instructions as a tool to increase patients' adherence to the medicine instructions. The literature review was the foundation for identifying the research gap and formulating the research questions and objectives, which are also presented.

Chapter three describes why Kisumu was chosen as the study location and for what reason childhood pneumonia and Amoxicillin syrup were chosen as the disease and medicine to develop pictorial medicine instructions for. Furthermore, it presents background information about Kenya, Kisumu, and the prevalence and perceptions of childhood pneumonia and the use of Amoxicillin syrup within this setting.

Chapter four describes the methodology and the findings of the development and pretesting of the pictorial medicine instructions that were used in the study.

Chapter five describes the study design. It describes the theoretical foundations of the project and how data were collected using a qualitative methodology. Furthermore, it

reflects upon working with a research assistant and the positionality and preconceptions of the researcher. Finally, the strengths and limitations as well as ethical considerations of this project are discussed.

Chapter six is a presentation of the findings of the study. It is divided into three main sections: 1) how caregivers administered the Amoxicillin syrup; 2) Explanations that the caregivers gave about the reason they administered the Amoxicillin syrup the way they did; 3) Caregivers' understanding, perceptions and recommendation for future use of the pictorial medicine instructions.

Chapter seven consist of an in-depth discussion of the findings that are reported in chapter six. It presents recommendations for future studies and for the use of pictorial medicine instructions for Amoxicillin syrup to treat childhood pneumonia in Kenya. Finally it provides an overall conclusion.

2. Literature review and research questions

This chapter first describes how relevant sources for the literature review were identified. It then presents the information found in the literature about factors that influence adherence to antibiotic treatment instructions and about pictorial instructions for health messages. Furthermore, it describes the knowledge gap that was identified in the literature. Finally it presents the research questions and objectives of this study.

2.1 The literature search

Three different databases were used to search for relevant articles: PubMed, Web of Knowledge and Google scholar. All these three databases were used to search for relevant articles within the following three topics:

1. Antibiotics/adherence/medicine taking behaviour. Examples of keywords used for this topic are: Patient AND adherence AND antibiotics
2. Readability medicine labels. Examples of keywords used for this topic are: Readability AND Medicine labels
3. Pictograms for medicine instructions. Examples of keywords used for this topic are: Visual aids AND medicine instructions.

Keywords were chosen based on their relevance to the topic. A strategy for defining these words was to use the same keywords that were listed as search terms in relevant articles. Relevant articles were also used to identify other articles that the authors had referred to. Furthermore, the databases that were used show how often an article is cited; by going through these citation lists new articles were identified.

2.2 Factors that influence adherence to antibiotic treatment instructions

According to the definition by Dowse and Ehlers (2005) adherence is whether a patients' medicine taking behaviour corresponds with the medicine instructions or not. This differs from compliance where the patient 'just' has to follow the treatment regime from the prescriber (Cramer et al., 2008; Vermeire et al., 2001). The term compliance implies that a patient is either obedient or not, while adherence perceives

the patients medicine taking behavior as a decision that could be influenced by several factors.

Cost of treatment (Krueger, Felkey, & Berger, 2003) and the complexity of the treatment course (Eide, Hippe, & Brekke, 2012; Kardas, 2002, 2007) are factors that influence adherence. If a patient cannot afford all the necessary pills it will influence whether every dose will be bought and therefore taken and a treatment regime of one pill a day for three days is easier to follow than a regime of three pills for five days.

Furthermore, communication between the health provider and the patient can influence adherence (DiMatteo, 2004; Krueger, Felkey, & Berger, 2003; Vermeire et al., 2001; Zolnierek & DiMatteo, 2009). A patient is more likely to adhere when the health provider who gives the oral medicine instructions is a good communicator and less likely to adhere when the health providers is a poor communicator. Zolnierek and DiMatteo (2009) argue that communication might be the central aspect of patient adherence because “it improves the transmission and retrieval of important clinical and psychological info, facilitates patient involvement in decision making, allows open discussion of benefits, risks and barriers to adherence, builds rapport and trust and offers patients verbal and non-verbal support and encouragement”.

Another factor influencing adherence is the patient’s perceptions of disease and treatment (Davey & Hayes, 2002; Krueger, Felkey, & Berger, 2003; Kucukarslan, 2012; Lim & Teh, 2012; Oh et al., 2011). How a patient perceives his/her disease and the reason to take treatment influences the way the treatment will be taken: if the symptoms are seen as the disease, treatment will be taken in order to get rid of the symptoms. For example a patient who perceives a lung infection as cough is likely to stop treatment when the cough is gone. For example a patient could stop an antibiotic treatment after three days when the cough is gone even though the medicine should be administered for five days. In contrast, a patient who perceives a lung infection as such is more likely to continue to take the antibiotic treatment for five days to get rid of the infection.

Finally, a patient is more likely to adhere when treatment instructions are understood (Davey & Hayes, 2002; Dowse & Ehlers, 2005; Krueger, Felkey, & Berger, 2003; Ngoh & Shepherd, 1997; Vermeire et al., 2001). A patient who understands the information of what dose to give, how many times a day and how many days is more likely to adhere to this information. However, research focused on understanding medicine instructions found that it is difficult for a lot of patients to understand and accurately interpret the oral and written medicine instructions (Davis et al., 2006; Wolf et al., 2012). This is connected to health literacy, which is the total set of skills of print literacy, numeracy and oral literacy necessary to understand health messages (Berkman et al., 2011). Therefore, a person who has difficulties in reading, measuring a dose and/or understanding the oral instructions from the pharmacist is more likely to have difficulties in understanding treatment instructions.

2.3 Pictorial materials to increase understanding and adherence to health messages

A way to address the problem of low health literacy is to include pictorials on medicine labels (Dowse & Ehlers, 2001, 2004, 2005; Houts et al., 2006; Houts, Witmer, Egeth, Loscalzo, & Zabora, 2001; Katz, Kripalani, & Weiss, 2006, Ngoh & Shepherd, 1997; Mansoor & Dowse, 2003). Ngoh and Shepherd (1997) link the development of effective pictorial instructions to the Social Learning Theory of Identificatory Processes (Bandura, 1977). According to this model there are four processes between presenting modelled behaviour and the actual behaviour:

1. Attention process: the observer has to pay attention to the modelled behaviour
2. Retention, mental rehearsal: the observer must represent the observed behaviour cognitively
3. Motor reproduction processes: the observer has to translate the representation of the observed behaviour into representations of appropriate actions
4. Motivational processes: the observer has to be motivated to perform the behaviour

Ngoh and Shepherd (1997) argue that for pictorial medicine instructions to be effective they have to get the patients' attention, and the information must be presented in a way that makes it easy to remember it. Finally, the messages must be

perceived as relevant and attainable and should motivate the patients to follow the instructions.

This is supported by studies on pictorial materials in health education and promotion. They showed that pictorials which are culturally acceptable, simple and make sense to their audience, do not only increase attention to the message, they also increase the likelihood that patients will understand and remember the message (Dowse & Ehlers, 2004, 2005; Dowse & Ehlers, 2001; Houts et al., 2006; Houts et al., 2001; Katz et al., 2006; Mansoor & Dowse, 2003; Ngoh & Shepherd, 1997). Furthermore, adherence to health instructions from health care providers increases when the patients are given easily accessible written instructions accompanied with pictograms (Chuang, Lin, Wang, & Cham, 2010; Davis et al., 2006; Wolf et al., 2012).

2.4 Pictorial medicine instructions to increase adherence to antibiotic treatment instructions

Pictorial materials do not only increase understanding and adherence to health instructions and messages, it can also lead to improved understanding and adherence to antibiotic treatment instructions. Three studies in clinics in Cameroon (Ngoh & Shepherd, 1997), South Africa (Dowse & Ehlers, 2005) and the United States (Yin et al., 2008) have found that understanding and adherence to antibiotic instructions increased when the patients received pictorial based advice.

All the three studies compared a control group who received regular treatment instructions at the pharmacy when getting an antibiotic with an experimental group who received pictorial medicine instructions. These pictorials were given out by a trained pharmacist, or by a research assistant, who provided additional oral instructions on how to use the medicine and the pictorial instructions. Within a couple of days after they should have been finished giving or taking the treatment the participants were visited at their home (Dowse & Ehlers, 2005; Ngoh & Shepherd, 1997) or contacted by phone (Yin et al., 2008). During those visits or calls their understanding and adherence to the instructions was measured using quantitative methods: both understanding and adherence were measured by a predefined questionnaire with a scoring list. During the home visits adherence was also measured

through pill count, to check whether all the medicine had been taken (Dowse & Ehlers, 2005; Ngoh & Shepherd, 1997).

In all the three studies the participants who had received pictorial instructions scored better on both understanding and adherence than participants who had not received pictorial instructions. In the study by Dowse and Ehlers (2005) 95.2% of the participants who received the pictorials understood the treatment instructions and 89.6% of them adhered to these instructions, while 69.5% of the participants who did not receive the pictorials understood the treatment instructions and 71.5% adhered to them. In the study by Yin et al. (2008) none of the participants who received pictorial counselling reported an error in knowledge and only 9.3% of them was non adherent. These numbers are lower compared to the group who did not receive pictorial based counselling, 15.1% of them had an error in knowledge and 38% was non adherent.

Ngoh and Shepherd (1997) included a second experimental group in their study who received an advanced organizer in addition to the pictorial instructions. This advanced organizer bridges the gap between what the learner already knows and what the learner needs to know before the new task can be learned successfully. In this study farming was used a paradigm for proper use of antibiotics to show what happens if the patient does not adhere to the treatment instructions and stops taking antibiotics prematurely. They found that participants who received both the pictorial instructions and the advanced organizer explaining for what reasons they have to adhere to these instructions achieved the highest understanding. The group who received the pictorials and the advanced organizer scored 6.89, the group who received the pictorials scored 5.77 and the control group scored 4.65 on a scoring list from zero to seven. Both experimental groups adhered significantly better than the control group, however there was no significant difference in adherence score between the two experimental groups: 94.6% of the participants who received the pictorials and the advanced organizer adhered to these instructions, 89.5% of the participants who received the pictorials was adherent and 77.5% of the control group was adherent.

2.5 Identified knowledge gap in the literature

Previous studies have found that pictorial instructions can lead to increased understanding and adherence to medicine instructions (Dowse & Ehlers, 2005; Ngoh

& Shepherd, 1997; Yin et al., 2008). However, due to their quantitative design it remains unclear in which way and for what reason pictorial based advice leads to an increased adherence to the instructions. The pictorial instructions were used to explain the instructions to the participants, who took these pictorial instructions home. However, it is not mentioned in the studies whether the participants used these pictorials in any way while administering the medicine.

Secondly, adherence was measured by a self-reporting questionnaire and by pill count. Pill count is a popular method because it is an easy and objective measurement to test for adherence (Kardas, 2002). However, counting pills does not give insight in how and when the pills were taken or if the same person took all pills. Thus if all pills are gone it could still be that the medicine was taken the wrong way. Self-reporting questionnaires can provide insight into how and when the pills were taken. The studies by Dowse and Ehlers (2005) and Ngoh and Shepherd (1997) used self-reporting measurements, but not to measure adherence since their criteria for being adherent or not was whether all the pills were taken. These studies show that participants who have received the pictorial instructions had less pills left than the participants who did not receive these instructions. They do not provide any insight concerning the adherence to the treatment instructions.

Furthermore, due to the data collection procedure it is likely that communication had an influence on the findings. Communication between patients and health providers has been found to be an important influential factor for medicine adherence (Zolnieriek & DiMatteo 2009). Explaining treatment instructions by using pictorials as an instruction tool most likely influence communication positively. Furthermore, in two studies the pictorial counselling was given by research assistants after the participants had already received the antibiotic and instructions from the regular pharmacists (Ngoh & Shepherd, 1997; Yin et al., 2008). Thus caregivers who received the pictorial instructions also received additional communication about the treatment instructions.

According to the Heuristic-Systematic Model of Information Processing (HSM) it could be that in all three studies respondents who received the pictorial instructions were guided by the additional and/or improved oral instructions instead of the

pictorials. The HSM is a communication model developed by Chaiken that provides an explanation for how people receive and process messages (Maio & Haddock, 2010). The guiding belief is the *sufficiency principle* (Chaiken & Trope, 1999; Maio & Haddock, 2010). According to this principle people will often process with the least amount of effort when information is presented to them to minimize their use of cognitive resources. In the HSM this is referred to as *heuristic processing*. The other way of processing is *systematic processing*, when people process more detailed information. This involves comprehensive and cognitive processing and takes a lot of effort. According to the HSM people are more likely to process heuristically and will only process systematically when they feel motivated and capable (Chaiken & Trope, 1999; Maio & Haddock, 2010). Therefore it is possible that many respondents who received the pictorials were guided by the oral instructions since it requires less use of their cognitive resources than the pictorial medicine instructions. It is thus unclear what actually made the difference to understanding and adherence: the pictorial instructions or communication.

Finally, all the studies do not mention for what reason the participants received the antibiotics treatment. Perception of disease and treatment has been listed as an influencing factor of treatment adherence (Davey & Hayes, 2002; Krueger, Felkey, & Berger, 2003; Kucukarslan, 2012). Therefore the participants' perceptions of the disease they were treating could have had an influence on how they treated their disease and thus on understanding and adherence to the treatment instructions.

2.6 Research questions and objectives of this study

To address the knowledge gaps that were identified in the literature the study aims to answer the following three questions:

- How do caregivers¹ give an antibiotic treatment?
- For what reasons do caregivers give an antibiotic treatment the way they do?
- Does including pictorial medicine instructions with an antibiotic medicine have an influence on how treatment is given? If so, in what way?

¹ The study population are caregivers. The pictorial instructions used to investigate the research questions were for Amoxicillin syrup to treat pneumonia in children younger than five years. More

To answer these questions this study focuses on the following specific objectives:

- Explore how treatment instructions are given by pharmacists
- Explore how caregivers understand these treatment instructions
- Explore how caregivers adhere to these treatment instructions
- Explore how caregivers give the antibiotic treatment
- Explore caregivers' understanding of the pictorial medicine instructions for the antibiotic syrup
- Explore the influence of the pictorial medicine instructions on the way caregivers give the antibiotic treatment
- Explore the influence of communication with the health providers on the way caregivers give the antibiotic treatment
- Explore how local perceptions of childhood pneumonia and treatment influenced the way caregivers give the antibiotic treatment
- Explore the influence of possible other factors on how caregivers give the antibiotic treatment

3. Background

This section first describes the rationale for selecting Kisumu as study location and childhood pneumonia and Amoxicillin syrup as disease and treatment to be studied. It then gives background information about Kenya and Kisumu. Finally it gives a description about childhood pneumonia and about treatment of childhood pneumonia in Kenya.

3.1 Rationale for selecting Kisumu, childhood pneumonia and Amoxicillin syrup

During the planning stage of this project, April and May 2013, the intention was to collaborate with Program for Appropriate Technology in Health (PATH), an NGO based in Seattle. PATH was collaborating with the United Nations Children's Fund (UNICEF) to develop and test pictograms for new dispersible Amoxicillin tablets to treat childhood pneumonia (PATH, 2013). At that time different pictograms were already used in Cambodia, Myanmar, Rwanda and Mozambique, and PATH was developing pictograms and pretesting the pictorial instructions with health providers in Kisumu, Kenya. PATH would provide a prototype of these pictogram instructions for this study. Since the Amoxicillin dispersible tablets were not available at the public clinics yet this prototype would be adapted for Amoxicillin syrup. Thus, this study would be conducted in Kisumu on Amoxicillin syrup for childhood pneumonia using these pictorial medicine instructions.

However, at the end of June 2013 PATH wanted an agreement with the University of Oslo that the data collected for my study would not be published beyond the MPhil thesis work. The university did not allow a collaboration that puts a limit on publishing. PATH decided it was most beneficial for both parties to proceed with the projects independently. At this stage the project was already given ethical approval in Norway. Furthermore, the study was already affiliated with the Institute of Anthropology in Nairobi and applications were already registered for the research permit and for ethical approval to the research committee in Nairobi, Kenya. Furthermore, there were already contacts established in Kisumu. For these reasons, I decided to continue the project as planned without collaboration with PATH on pictorial medicine instructions for Amoxicillin syrup to treat childhood pneumonia in Kisumu, Kenya.

3.2 Background Kenya

Kenya (figure 1) has a population of 40,512 million people with a growth rate of 2.6 between 1998 and 2008 (World Health Organization, 2012a). The majority of the population, 78%, lives in rural areas and 19.7% of the population lives in absolute poverty. Adult literacy is expected to be around 74%. In 2008 the life expectancy was 54 years and the under five-mortality rate was 84 out of 1000 live-births. To reach the fourth Millennium Development Goal this should be brought down to 33 out of 1000 live births by 2015 (WHO Regional Office for Africa, 2010).



Figure 1. Kenya (Retrieved from Google maps)

With an estimation of 42 different ethnic groups the country has a diverse population. The Kikuyu is the biggest group, representing 22% of the population, followed by the Luhya, 14%, and the Luo, 13%. There are 69 languages spoken and two of them, English and Kiswahili, are the official ones. The majority of the population is Christian, however the coastal area is predominantly Muslim (Central Intelligence Agency, 2014).

After two decades of low economic status the country has experienced economic growth since 2003 (WHO Regional Office for Africa, 2009). As a response the Government has increased its budget for development priorities such as health, education, infrastructure and rural development. Even though social indicators are improving, there are still major challenges to overcome such as corruption, reducing administrative barriers and public safety (WHO Regional Office for Africa, 2009).

3.3 Background Kisumu

The fieldwork was conducted in Kisumu district, specifically in Kadibo division of Kisumu East District. Kisumu district is located in Western Kenya (figure 2). The capital is Kisumu city, which is located directly on the shores of lake Victoria. The district's population is 968.909 and the district is relatively densely populated compared with the rest of Kenya (Kenya open data survey, 2014).

The vast majority of the population is Luo. Even though the majority of the population speaks English and Kiswahili, Dholuo is the dominant language in the district. Because of its location, fishing is an important source of income together with rice farming because of rice plains next to the lake.



Figure 2. Kisumu area
(Retrieved from Google Maps)

3.4 Childhood pneumonia in Kenya

This section describes the prevalence of childhood pneumonia and the perceptions and health seeking behaviour related to the disease. Furthermore, it gives information about Amoxicillin syrup, one of the antibiotics that are prescribed for childhood pneumonia in Kenya.

3.4.1 Prevalence of childhood pneumonia

Pneumonia is an extreme lower respiratory tract infection affecting the lungs (Wardlaw et al., 2006). When children suffer from pneumonia they can experience many symptoms such as cough, high fever and difficulties in breathing leading to rapid breathing (Wardlaw et al., 2006). Young children can also experience loss of appetite and unconsciousness (Wardlaw et al., 2006).

With 85 under five deaths per 1000 live births Kenya has a high rate of child mortality (World Health Organization, 2012a). Pneumonia is one of the leading causes for childhood mortality causing 17% of all child deaths in Kenya (World Health Organization, 2012a). These high numbers of mortality are caused by different

factors, with poverty as the underlying main factor. The factors are: poor nutrition, scarce access to clean water and sanitation and weak availability, access and utilization of health services (WHO Regional Office for Africa, 2009). Another contributing factor is low level of education of the mothers. This can influence recognition of symptoms, health seeking behaviour and how treatment is given (Burton et al., 2011; Irimu, Nduati, Wafula, & Lenja, 2008; Simiyu, Wafula, & Nduati, 2003; Taffa & Chepngeno, 2005, WHO Regional Office for Africa, 2009).

In 2011 the government introduced the pneumococcal vaccine. This first dose is given to children six weeks of age, the second dose to children ten weeks of age and the third dose to children 14 weeks of age. (Republic Kenya Ministry of Health, 2013). This vaccine prevents severe pneumonia and is a major step forward in preventing death caused by pneumonia in children under five (United Nations Children's Fund, 2012).

3.4.3 Perception of childhood pneumonia and health seeking behaviour

Studies conducted in Kenya focusing on health seeking behaviour for child illness such as pneumonia have found that medical care is often not sought and when treatment is sought at the health facilities it is usually for the severe cases (Burton et al., 2011; Taffa & Chepngeno, 2005). Determinants of health seeking behaviour that have been found are access and costs of the services but also recognitions of symptoms and beliefs about the illness (Irimu et al., 2008; Simiyu et al., 2003; Taffa & Chepngeno, 2005). The latter means that when the symptoms of pneumonia are not recognized as signs of pneumonia it is less likely that medical care will be sought. Furthermore, the perception of pneumonia will also influence adherence to homecare messages or treatment instructions (Irimu et al., 2008).

There are some studies that assessed perceptions of childhood pneumonia in Kenya. A study in Baringo district looked at how childhood pneumonia was perceived by mothers (Simiyu et al., 2003). Most mothers described it as fever. Another study, looking at community understanding in Kiambu district at the outskirts of Nairobi, also found that fever was perceived to be closely linked to pneumonia (Irimu et al., 2008). Without fever a child was unlikely to have pneumonia. Both studies describe specific

names for the different stages of pneumonia and how severe these stages are perceived. For example in the study by Irimu et al. (2008) they found severe pneumonia was referred to as '*rimunia*', of which high fever is the main symptom together with a range of other possible symptoms such as cough and chest in-drawing. Furthermore, the respondents said that when a child is suffering from '*rimunia*' care at a health facility have to be sought immediately.

3.5 Amoxicillin syrup to treat childhood pneumonia

Death by pneumonia is preventable when it is treated with antibiotics at an early enough stage (United Nations Children's Fund, 2012; Wardlaw et al., 2006).

According to the recommendations of the World Health Organization first line treatment of childhood pneumonia is dispersible Amoxicillin (World Health Organization, 2011, 2012b).

In Kenya the pneumonia protocol, to help health providers with prescribing treatment, is described in the Basic Paediatric Protocol (Ministry of Health Republic of Kenya, 2013). Treatment depends on the severity of the disease. For very severe pneumonia Oxygen, Ampicillin or Penicillin and Gentamicin are the guideline. For severe pneumonia Benzyl Penicillin is the guideline. For non-severe pneumonia Co-trimoxazole is the first line treatment, except when this has been administered for pneumonia before. In that case the second line of treatment is recommended, Amoxicillin. Amoxicillin is listed as a vital medicine and is on the core list, which means that it is a medicine of highest therapeutic significance and that it should always be in stock and available (Republic Kenya Ministry of Public Health and Sanitation, 2011).

The Kenyan Government has recently made the decision to follow WHO guidelines and make the shift to Amoxicillin as the first line treatment for childhood pneumonia, with dispersible tablets being made available countrywide. The dispersible tablets are already available in some institutions, but are not yet commonly available. In response pharmacists prescribe Amoxicillin more frequently as a first line treatment for childhood pneumonia.

Amoxicillin syrup preparation

Amoxicillin is available in syrup and capsules. The syrup is often prescribed to children younger than five years. It comes in powder form, and needs to be constituted before given to the child. Depending on the manufacturer it has to be mixed with 60 ml, 80 ml or 100 ml of water. The bottles come with a measuring cup or a line on the bottle that indicates up to where to fill the bottle.

Treatment course

The medicine should be given three times a day with an eight hourly interval for five days. The correct paediatric dose of the Amoxicillin syrup that is provided at the public clinics is 20mg/kg daily (figure 3). According to the Paediatric protocol a child, who has a normal weight and height for his/her age, should get the following dose three times a day:

- Between one month and one year should get 2.5 millilitres.
- One year up to three years should get five millilitres.
- A child of three years up to five years should get 10 millilitres.

The medicine should be poured out after a week; it should not be kept and used again.

Cost and access

Amoxicillin is sold in pharmacy shops, with or without prescription and is available free of cost at the public clinics. There is an instruction leaflet on how to use the drug correctly that comes as an insert with the Amoxicillin syrup provided at the clinics (figure 3).

ALIMOX

Amoxicillin 250mg Capsules
Amoxicillin 500mg Capsules
Amoxicillin Dry Powder for reconstitution

COMPOSITION:
Each Capsule contains:
- 250mg of Amoxicillin as Amoxicillin trihydrate B.P
- 500mg of Amoxicillin as Amoxicillin trihydrate B.P
Each 5ml of the reconstituted Dry Syrup contains: 125mg of Amoxicillin as Amoxicillin trihydrate B.P

DESCRIPTION:
Amoxicillin is a semisynthetic antibiotic with a broad spectrum of bactericidal activity against many gram-positive and gram-negative micro-organisms. Chemically it is (2S,5R,6R) - 6 - [(R) - (-) - 2 - Amino - 2 - (p - hydroxyphenyl) acetamido] - 3,3 - dimethyl - 7 - oxo - 4 - thia - 1 - azabicyclo [3.2.0] heptane - 2 - carboxylic acid trihydrate.

CLINICAL PHARMACOLOGY:
Mechanism of Action
Bactericidal; inhibit bacterial cell wall synthesis. Action is dependent on the ability of penicillins to reach and bind penicillin-binding proteins (PBPs) located on the inner membrane of the bacterial cell wall. PBPs (which include transpeptidases, carboxypeptidases, and endopeptidases) are enzymes that are involved in the terminal stages of assembling the bacterial cell wall and in reshaping the cell wall during growth and division. Penicillins bind to, and inactivate, PBPs, resulting in the weakening of the bacterial cell wall and lysis.

Pharmacokinetics: Absorption:
Amoxicillin is generally stable in the presence of acidic gastric secretions, and 74 - 92% of a single oral dose of the drug is absorbed from the GI tract. Amoxicillin is more completely absorbed from the GI tract than is Ampicillin, and peak serum concentrations of Amoxicillin are generally 2 - 2.5 times higher than those attained with an equivalent oral dose of Ampicillin. As oral dosage of Amoxicillin is increased, the fraction of the dose absorbed from the GI tract decreases only slightly and peak serum concentrations and areas under the serum concentration-time curves (AUCs) increase linearly with increasing dosage.

Distribution:
Penicillins are widely distributed to most tissues and body fluids, including peritoneal fluid, blister fluid, urine (high concentrations), pleural fluid, middle ear fluid, intestinal mucosa, bone, gallbladder, lung, female reproductive tissues, and bile. Distribution into the cerebrospinal fluid (CSF) is low in subjects with non-inflamed meninges, as is penetration into purulent bronchial secretions. Penicillins cross the placenta and are distributed into breast milk. Peak serum concentrations are usually reached 1 - 2 hours after oral administration of Amoxicillin capsules or oral suspension in fasting and non-fasting adults. Although presence of food in the GI tract reportedly results in lower and delayed peak serum concentrations of Amoxicillin, the total amount of drug absorbed does not appear to be affected.

Elimination:
Primarily renal - (glomerular filtration and tubular secretion). Hepatic metabolism accounts for less than 30% of the elimination of most penicillins, with the exception of nafcillin and oxacillin.

INDICATIONS:
Amoxicillin has activity against *Haemophilus influenzae*, *Escherichia coli*, and *Salmonella* and *Shigella* species and also retains activity against penicillin - sensitive gram-positive bacteria. However, many Enterobacteriaceae and *H. influenzae* are resistant as a result of beta - lactamase production. Amoxicillin has the same spectrum of activity as ampicillin, although amoxicillin has slightly better activity against *Enterococcus faecalis*, *E. coli*, and *Salmonella* sp., and slightly less activity against *Shigella* sp.

CONTRA-INDICATIONS:
Amoxicillin shares the toxic potentials of the penicillins, including the risk of hypersensitivity reactions, and the usual precautions of penicillin therapy should be observed.

Prior to initiation of therapy with Amoxicillin, careful inquiry should be made concerning previous hypersensitivity reactions to penicillins, cephalosporins, or other allergens. There is clinical and laboratory evidence of partial cross-allergenicity among penicillins and other beta-lactam antibiotics including cephalosporins and cephamycins. Amoxicillin is contraindicated in patients who are hypersensitive to any penicillin.

Because a high percentage of patients with infectious mononucleosis have developed rash during therapy with aminopenicillins, amoxicillin probably should not be used in patients with the disease.

Amoxicillin should be used during pregnancy only when clearly needed. However, Amoxicillin has been administered to pregnant women without evidence of adverse effects to the fetus, and use of the drug is currently included in the US Centers For Disease Control and Prevention (CDC) recommendations for the treatment of chlamydial infections during pregnancy.

SIDE EFFECTS:
May cause serious allergic reactions in those with penicillin allergy. May cause nausea, vomiting and diarrhoea; notify your doctor or pharmacist immediately these symptoms occur.

WARNINGS: Renal, hepatic and haematologic systems should be evaluated periodically during prolonged therapy with Amoxicillin. Because Amoxicillin is distributed into milk and may lead to sensitization of infants, the drug should be used with caution in nursing women.

DOSAGE AND ADMINISTRATION:
Alimox (Amoxicillin trihydrate Capsules and Dry powder for reconstitution) is administered orally.
Amoxicillin dry powder for oral suspension should be reconstituted at the time of dispensing by adding the amount of water specified on the bottle to provide a suspension containing 125 mg of Amoxicillin per 5 ml.


Adult Dosage:
For mild to moderate infections of the ear, nose, or throat and skin; or genitourinary tract:
- 500 mg every 12 hours or 250 mg every 8 hours.
For the treatment of severe infections and for the treatment of mild, moderate, or severe lower respiratory tract infections:
- 875 mg every 12 hours or 500 mg every 8 hours

Paediatric Dosage:
For the treatment of infections of the ear, nose, or throat and skin; or genitourinary tract
Neonates and infants 12 weeks of age or younger,
- 30 mg/kg daily in divided doses every 12 hours.
3 months of age or older
For mild to moderate infections: 20 mg/kg daily in divided doses every 8 hours
For severe infection: 40 mg/kg daily in divided doses every 8 hours.
For the treatment of mild, moderate, or severe respiratory tract infections in paediatric patients 3 months of age or older
40 mg/kg daily in divided doses every 8 hours.

STORAGE: Store Capsules and Dry powder in a cool dry place.
Keep out of reach of children.

NOTE: Shake reconstituted oral suspension well before use. Keep bottle tightly closed. **Any unused portion of the reconstituted suspension must be discarded after 7 days.**

PRESENTATION:
Alimox dry syrup is available in 60ml and 100ml plastic bottles containing an almost white powder which on reconstitution gives a yellow suspension.
Alimox capsules are maroon/peach hard gelatin capsules printed sphinx, available in jars containing 1000 capsules, 500 capsules and in blisters of 10x10 capsules.



Sphinx
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Figure 3. Instructions leaflet Amoxicillin syrup.

4. Development and pretesting of the pictorial medicine instructions

Pictorial medicine instructions for the Amoxicillin syrup had to be developed before they could be used in this study. This chapter explains the purpose of developing and pretesting the pictorial medicine instructions of the Amoxicillin syrup. Secondly, it describes how the pictorial medicine instructions were developed and then how they were pretested. Finally the findings from the pretesting are presented and discussed.

4.1 The purpose of developing and pretesting pictorial medicine instructions for Amoxicillin syrup

Pictorial instructions can be successful to communicate messages about medicine instructions (Dowse & Ehlers, 2005; Ngoh & Shepherd, 1997; Yin et al., 2008). However, in order to communicate messages effectively through pictograms, they need to be carefully developed and pretested (Dowse & Ehlers, 2001; Fussell & Haaland, 1976; Haaland, 1984; Haaland, Akogun, & Oladepo, 2000; Houts et al., 2006; Katz et al., 2006; Ngoh & Shepherd, 1997). People who have a high level of education and live in urban modern settings are often developing the pictograms for people who have a low level of education and live in rural and relatively poor settings. This creates a communication gap in which the users recognize the messages in the pictorial materials differently than intended by the developers. An example is a poster of an anti-smoking campaign in Nepal (figure 4, from Haaland, 1984). After this poster was produced for use, a study found that only 10% of their respondents understood the intended message. The others recognized the poster as showing a devil, a sick face or a blind man (Haaland, 1984).



Figure 4. Anti-Smoking Campaign
Nepal

Pretesting pictorial materials can avoid such misinterpretations. In pretesting the target audience of the pictorial materials are interviewed about these materials, when

they are still in a draft stage. This provides an insight into the literal understanding of the pictograms and in the interpretation of meaning of the pictorial materials. The literal interpretation means the users' recognition, familiarity and acceptability of each separate object in the pictograms (Haaland, Akogun & Oladepo, 2000). The interpretation of meaning means whether the respondents grasp and understand the intended messages in the instructions (Haaland, Akogun & Oladepo, 2000). Based on the assessment of the literal interpretation and the interpretation of meaning the pictorial materials can be adjusted. When the potential users recognize, accept and are familiar with the pictograms and they perceive the messages as intended, it is likely that the pictorial material will be a useful tool for communication (Houts et al., 2006; Katz et al., 2006; Haaland, 1984), and that the pictorial instructions will be used as intended, also known as the operational use (Haaland, Akogun & Oladepo, 2000).

This study focussed on pictorial medicine instructions for Amoxicillin syrup for childhood pneumonia. Such instructions did not yet exist and therefore had to be developed and pretested before they could be used in this study. The initial idea was to use the pictorial medicine instructions developed by PATH. Even though the collaboration was stopped, PATH still provided a prototype of the Amoxicillin dispersible tablets with permission to use in this study (figure 5). However, there were several reasons to not use their prototype and develop new instructions instead.

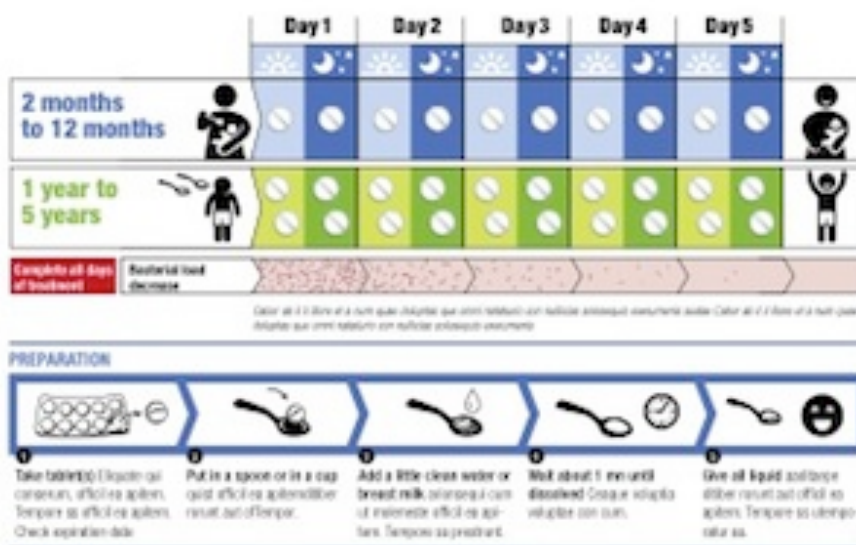


Figure 5. PATH prototype pictorial medicine instructions for Amoxicillin dispersible

First of all Amoxicillin dispersible was not provided at the public clinics when this study was conducted, and thus this study focused on Amoxicillin syrup instead. The instructions for the Amoxicillin syrup differed from the Amoxicillin dispersible regarding preparation, dose for age and treatment regime. Furthermore, the pictograms for the Amoxicillin dispersible instruction leaflet consisted to a large extent of abstract symbols, while previous research on pictograms have shown that abstract symbols are often more difficult to recognize, especially for low-literate audiences (Houts et al., 2006; Fussell & Haaland, 1976). This was for example found in a study conducted in Nepal (Fussell & Haaland, 1976). Different pictograms of a tree were compared: the abstract drawing was recognized by 21% of the respondents whereas the more realistic shaded line drawing was recognized by 79% of the respondents (figure 6).



Figure 6. Left is a shaded line drawing of a tree and right is an abstract drawing of a tree

Finally, PATH did not communicate whether they had pre-tested this prototype for understanding with caregivers, but since their original plan was to pretest with health providers only it was highly unlikely that the instructions were tested for understanding amongst caregivers. Therefore, even if the pictorial instructions would be adapted according to the Amoxicillin syrup instructions, there would have been a possibility that the messages would not be recognized as intended by the caregivers in this study.

4.2 Development of the pictorial medicine instructions of the Amoxicillin syrup

This section describes how the pictorial medicine instructions were developed. First it describes learning from previous studies that were used in the pictorial instructions for the Amoxicillin syrup. Secondly it describes the messages that had to be included in instructions according to health providers in Kisumu. Thirdly it presents the first version of the pictorial medicine instructions. Finally it describes how the final version was developed by the assessment of the literal interpretation and the interpretation of meaning.

4.2.1 Learning from previous studies

The style of the pictograms was based on recommendations for good understanding of pictograms from previous pretesting studies with pictorial materials (Fussell & Haaland, 1976; Haaland, 1984; Haaland, Akogun, & Oladepo, 2000; Houts et al., 2006; Ngoh & Shepherd, 1997):

- Simple shaded line drawings are best understood.
- Abstract symbols are often misunderstood.
- Too many details can create confusion.
- Cut off body parts are often misunderstood. It is better to use whole or half bodies.
- Keep the pictograms culturally neutral, so that the majority of the users can identify themselves with them. For example clothing: if the drawing is specific for women who live in a city, e.g. style of clothing and hair, then women who live in rural areas might not identify themselves with the persons in the drawings.

The way the information on the pictorial leaflet was organised was copied from a pictorial medicine instruction leaflet for Lapdap (chlorproguanil-dapsone), a medicine for falciparum malaria that eventually never came on the market. The instructions of Lapdap (chlorproguanil-dapsone), were pretested with 282 community members and 96 health providers in Kenya and Tanzania in 2007 (Haaland 1a, unpublished). The leaflet was folded. The front page listed key message about the medicine and pictograms showed how to prepare the medicine. Inside the leaflet a table showed information about the treatment course: the number of days, how many times a day, and which dose to administer to a child of a certain age group. Furthermore, drawings

of square boxes with red dots for each day visualized how the parasites are reducing as you give the medicine. On day one there are a lot of red dots showing a lot of parasites, and every day there are less dots meaning that the parasites are reducing as you give the medicine. When you give the last dose all dots are gone, meaning that there are no parasites anymore. On the back of the leaflet there was an adherence story to reinforce the information about the reducing parasites. The adherence story contained pictograms of a child that recovers every day and of the parasites that reduce in the body when administering the medicine. This story explains the reason why you have to complete a full treatment course; even if the child is already looking better there is still disease in the body and the child is not yet fully recovered.

The parasite concept is also included on the medicine package of Coartem dispersible (artemether – lumefantrine), a malaria medicine that has been on the market since 2010 (figure 7). The pictorial instructions of the Coartem dispersible (artemether – lumefantrine) were pretested on 160 health workers, 461 community members and 110 community health workers in four different countries of which Kenya (Haaland 1b, unpublished). Both the Lapdap (chlorproguanil-dapsone) and Coartem (artemether – lumefantrine) studies showed that the majority of the respondents comprehended the idea that you have to administer a complete treatment course for the disease to disappear (Haaland 1a & 1b, unpublished). In addition, even if the respondents were not familiar with the concept of parasites, the majority connected the red dots with something bad that you have to get rid of.

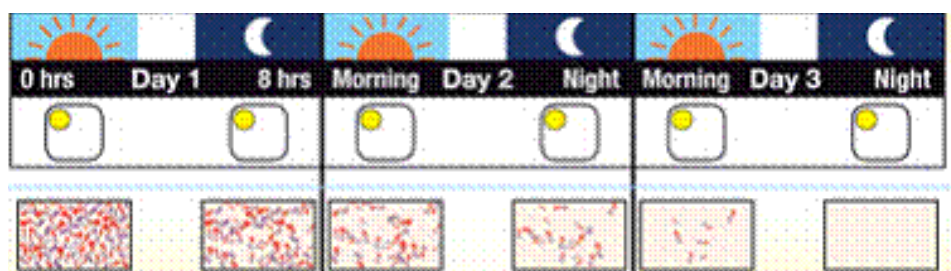


Figure 7. From Coartem dispersible. The red dots in the square boxes are showing how much parasites there are in the body every day.

An influential factor for adherence is the patient's or caregiver's perceptions of disease and treatment (Davey & Hayes, 2002; Krueger, Felkey, & Berger, 2003; Kucukarslan, 2012; Lim & Teh, 2012; Oh et al., 2011). A message about the

importance of completing a full treatment course in order to get rid of all the pneumonia bacteria, or to get rid of something bad in the body, could potentially influence adherence to the medicine instructions. For this reason the parasite concept was copied for the pictorial medicine instructions for the Amoxicillin syrup. The PATH prototype also copied this parasite concept from the studies above.²

4.2.2 Messages to include in the pictorial medicine instructions according to health providers

Exploratory interviews were conducted with 17 health providers working at five different clinics in the Kisumu district³, to find out what information to include in the pictorial medicine instructions for the Amoxicillin syrup, These health providers were pharmacists and doctors working with children under five years and were thus experienced in prescribing and giving oral instructions to caregivers on Amoxicillin syrup.

The health providers listed the following messages as key contents for the pictorial medicine instructions:

- Preparation: To prepare the medicine you have to add clean water that has been boiled or filtered, up until the line and shake well. Twelve of the health providers said that the pictorial instructions should tell that you have to add the water bit by bit and shake in between so that the medicine dissolves well in the water.
- Dose: A child of one month up to one year should get 2.5 ml. A child of one year up to three years should get five ml. A child of three years up to five years should get 10 ml. Six health providers argued it would be better to use spoons as measurements because caregivers are more familiar with using a spoon than a bottle top.
- Treatment regime: The medicine should be given every eight hours. Three of health providers said that it was unrealistic that caregivers would give the medicine exactly every eight-hour. They suggested to instruct on giving a dose in the morning, midday and evening

² Ane Haaland shared these concepts with PATH when we were still collaborating with PATH in May

³ For a detailed description of the setting see section x.x.x in the research design and methodology chapter.

The medicine should be given for five days. Four health providers said that the pictorial instructions should include a message telling the caregivers that you can give it up to seven days in case the symptoms have not yet disappeared.

- Pour out remaining: The medicine that remains should be poured out after a week; it should not be kept and used again. All health providers listed this message.

4.2.3 The first version of the pictorial medicine instructions

The first version of the instructions was based on the learning from previous studies and on the messages about Amoxicillin syrup that were listed by the health providers. Kiswahili was chosen as the language for the written text because it is the national language in Kenya. The pictorial leaflet was developed using a simple cut, paste and copy technique. Not only because this was most practical in the setting, but also because this clearly shows that the pictorial leaflet was in the draft stage. If people see that the leaflet is still a draft and not yet finished, they could be more interested and willing to discuss the materials because they feel their feedback actually matters (Haaland, 1984).

The first version of the pictorial medicine instructions was a folded paper leaflet (1/2 A4 format):

Front page



Figure 8a. Front page version A1

The pictograms on the front page intended to show:

- A mother holding a child. The mother looks concerned. The child shows signs of pneumonia: fever and cough
- A hand holding the medicine bottle, and a hand pouring water into that bottle
- A hand shaking the medicine bottle

This was tested by assessing the literal interpretation.

The front page intended to display the following messages:

- The instructions are for Amoxicillin syrup to treat pneumonia
- To prepare the medicine you have to add water to the powder and shake it well
- You have to give the medicine three times a day for five days
- Pour out the remaining syrup after five days

This was tested by assessing the interpretation of meaning of the pictorial instructions.

Inside



Figure 8b. Inside version A1

The pictograms on the inside intended to show:

- A mother holding her child and giving the medicine
- A child between 2 months and 1 year⁴
- A measuring cup showing 2.5 ml
- A child between 1 year and 3 years⁴
- A measuring cup showing 5 ml
- A child between 3 years and 5 years⁴

⁴ These 3 drawings were copied from the Lapdap instructions. In a later version of the pictorial instructions they were replaced by drawings made by Bosco. These new drawings can be found in the findings section of this chapter

- A measuring cup showing 10 ml
- A sun coming up, a sun in the middle of the day, the moon
- The boxes with diminishing numbers of dots as representing pneumonia

This was tested by assessing the literal interpretation.

The inside intended to display the following messages:

- A child between one month and one year should be given 2.5 millilitres
- A child between one year and three years should be given 5 millilitres
- A child between three years and five years should be given 10 millilitres
- The medicine should be given three times a day, in the morning, around lunch hour and in the evening
- The medicine should be given for five days
- On the first day pneumonia is high in the body and it reduces every day you give the medicine. At the sixth day you have given all the medicine and there is no pneumonia anymore.

This was tested by assessing the interpretation of meaning of the pictorial instructions.

Back page



Figure 8c. Back page version A1

The pictogram on the back page intended to show:

- The sun as representing a day
- A mother holding a child. The mother looks concerned. The child has fever and is coughing
- A mother holding a child. The mother looks concerned. The child looks weak
- A mother holding a child. The mother looks a neutral. The child sits on her lap.

- A mother holding a child. The mother looks happy. The child stands next to her.
- A mother and a child. The mother looks happy and the child stands on his/her own.
- The dots as representing pneumonia

This was tested by assessing the literal interpretation.

The back page intended to display an adherence story including the following messages:

- To cure pneumonia the medicine has to be given for five days continuously
- On the first day the child is feeling really sick, the second day the child is feeling a bit better, the third day the child is again feeling better, the fourth day the child is feeling better and start to look stronger and healthy again and on the fifth day the child is now feeling completely well.
- On the first day pneumonia is high in the body and it reduces every day you give the medicine until there is no pneumonia anymore on the sixth day once you have given all the medicine

This was tested by assessing the interpretation of meaning of the pictorial instructions.

4.2.4 Assessing literal interpretation and interpretation of meaning to develop the final version

The first version of the pictorial medicine instructions was modified based on the assessment on the literal interpretation of the individual pictograms and the interpretation of the meaning of the pictorial instructions of the potential users, the mothers. If objects within the drawings were understood differently than what the pictogram intended to show, the pictograms were adjusted using the visual perceptions principles (section 3.2.1), and if messages were interpreted differently than intended, the aspects of the pictorial instruction that created this misinterpretation were modified.

The first version was modified into several newer versions throughout the pretesting until all the pictograms and messages were well recognized and understood in the final version. The different versions are presented in the findings section together with the justifications for why several aspects of the versions were modified.

4.3 Pretesting methodology

This section describes how the pictorial medicine instructions were pretested before they were used in the study. First it describes the aspects of an action research design. Secondly it describes the pre-test setting, sample, methods and procedure. Thirdly, it explains how the data was analysed. Finally the ethical permissions to conduct the pretesting research are mentioned.

4.3.1 Action research methodology

An action research design was used throughout the pretesting and the development of the pictorial medicine instructions. Dick (1997, in Costello, 2011, p. 5) defines actions research as “cyclic, with action and critical reflection taking place in turn. The reflection is used to review the previous action and plan the next one.” In other words by asking questions after an action such as ‘what worked and what did not?’ or ‘How should we do it differently next time’ the next action is planned.

This strategy was found appropriate for the development as well as the pretesting of the pictorial medicine instructions. New versions were developed based on assessment of literal understanding and interpretation of the meaning of the pictorial instructions from the respondents. By reflecting upon what was well understood and interpreted and what was not, the pictorial instructions were modified.

Critical reflection was also used to plan the pretesting interviews and focus group discussions. By asking questions such as ‘What went well during the interview and what did not?’ and ‘What could we do better next time’ skills for the subsequent interviews or focus group discussion could be improved. In addition, it gave an insight into what aspects to focus on when conducting the next interviews or focus group discussion.

4.3.1 Pretesting setting

4.3.1.1 Kilifi

The first phase of the development and pretesting of the pictorial instructions was conducted in collaboration with the MoH and with the KEMRI-Wellcome Trust research programme⁵ in Kilifi district, Kenya (figure 9). The pretesting interviews were carried out at several rural locations within Kilifi district: At Mpirani, Masangoni and Bisulubu, and at several clinics: Sokoke dispensary, Masangoni clinic and Todina dispensary. A focus group discussion was held at the KEMRI-Wellcome Trust research institute in Kilifi town.



Figure 9. Map Kilifi
(retrieved from Google maps)

Kilifi was chosen as a location because of local contacts that already had experience with pretesting and developing pictorial instructions. Ane Haaland, the main supervisor of this project, has worked in Kilifi on a number of research projects, including the development of pictorial medicine instructions for Lapdap (chlorproguanil-dapsone) and Coartem (artemether – lumefantrine) for falciparum malaria. During these projects she has trained local field workers in the method of pretesting pictorial instructions. She also trained a good artist to develop drawings for such instructions. One of her previous local field workers, Isaac Etemezi, was willing to be my research assistant for the project and the local artist, Bosco Kahindi, was available to draw the pictograms. Furthermore, Ane Haaland had to travel to Kilifi for further research with KEMRI colleagues during my fieldwork period. Therefore, developing and pretesting the pictorial medicine instructions in Kilifi was an opportunity to get supervision, to learn new skills and to work with an experienced staff.

4.3.1.2 Kisumu

The second phase of the pretesting of the final version of the instruction was conducted in Kisumu district. The pretesting interviews were carried out at Kisumu

⁵ KEMRI-Wellcome Trust is a research programme of which the main centre is in Coastal Kilifi. It is based on partnership between The Kenya Medical Research Institute (KEMRI), Oxford University and Wellcome Trust, an independent charity funding research to improve human health.

district hospital, Rabuor clinic and Nyang'ande dispensary. A focus group discussion was held at Kadette, a small rural town in Kilifi district.

The pictorial medicine instructions were briefly pretested in Kisumu to assess how they were perceived and if adjustments were needed before they were used in the main study. Pictograms can be cultural specific and objects or messages that are well understood in one culture could be misunderstood in another culture (Dowse & Ehlers, 2001; Haaland, Akogun, & Oladepo, 2000; Houts et al., 2001; Ngoh & Shepherd, 1997). Even though the aim of the pictograms was to keep them as culturally neutral as possible, there was a possibility that they would be understood differently in Kisumu compared to Kilifi, as the culture of the Luos is quite different from the culture of the Mijikenda, living in the Kilifi area on the Kenyan coast.

4.3.2 Pretesting sample

4.3.2.1 Sampling strategy

KEMRI -Wellcome Trust offered me to use their the KEMRI community representatives (KCR) database, so the initial sampling strategy was to use the this database to find potential respondents. KCRs are typical community members selected by their community to represent them in research projects conducted by KEMRI-Wellcome trust research programme, Kilifi. The two criteria to select a respondent were being a mother of a child younger than five and an educational level lower than class five in primary schools.

After conducting three interviews with the KCRs at their homes the research team discussed the position of the KCRs and decided to use a different sample strategy to select respondents for the following reason: KCRs are elected by their community to represent them and can thus perceive themselves as leaders. In addition, KCRs have been participating in research project before and have been more exposed to medicine information than most caregivers in the setting. Therefore, they are likely to grasp the pictorial instructions more easily than other caregivers.

All other respondents for the individual interviews in Kilifi and Kisumu were recruited using a purposive sampling strategy: caregivers who had a child between

two months and five years were recruited because they were the potential users of the pictorial medicine instructions. They were recruited at the clinics where they had come for treatment for their child who was younger than five years. They were asked if they would like to give their opinion about an instruction leaflet for a medicine, and that their input would be valuable because the instruction leaflet is being developed for mothers just like them. The aim was to only include caregivers who had little to no education. However, when recruiting the caregivers at the clinics I decided that it was threatening to approach the caregivers by immediately asking their education level and this could potentially also influence the way they perceive the pictorial medicine instructions. This is known as *stereotype threat* (Inzlicht, 2011), where a stereotype such as being illiterate could influence someone's performance, such as reading the pictorial medicine instructions.

During the period of data collection in Kilifi there were meetings for the KCRs at the KEMRI office and during this meeting mothers of children younger than five were asked to volunteer in the focus group discussion. This was an opportunity to conduct a focus group discussion within a short time with a homogenous group of mothers who potentially could use Amoxicillin syrup to treat childhood pneumonia.

Finally, the caregivers who participated in the focus group discussion in Kisumu were recruited through a mother who was part of a local women empowerment group. She was interested in the project and helped us gathering mothers of children younger than five in her area who were willing to participate in the discussion.

4.3.2.2 Sample description

In Kilifi, 17 caregivers were interviewed. Their average age was 30 years and their average schooling was class five in primary school. Fourteen of them were recruited at the clinics and three of them were KCRs. The average age of the KCRs that participated in the focus group discussion was 34.5 years and their average schooling was class eight in primary school.

In Kisumu, 20 caregivers were interviewed. The average age of the women was 34.5 years and the average schooling was class eight. Additionally, a focus group

discussion was conducted with six other caregivers, all mothers with an average age of 32 years and average schooling of class eight.

All the caregivers who were interviewed and who participated in the focus group discussion had at least one child between one month and five years.

4.3.3 Pretesting methods

4.3.3.1 Semi-structured interviews

Semi-structured interviews were conducted throughout the whole pretesting phase.

The aim of the interviews in Kilifi was to assess the caregivers' recognition, familiarity and acceptability of the pictograms and to assess what messages the caregivers identified. Questions that were asked were for example: 'Could you describe what you see here?' to test for literal interpretation, or 'What do you think this is trying to show?' to test for interpretation of meaning. In case they had problems recognizing a pictogram they were given a clue because in case the literal interpretation is misunderstood the interpretation of meaning will be automatically misunderstood as well. For example, one mother saw the pneumonia dots as the dose to give every day. She was then told that the dots intended to show pneumonia, and asked to describe what she thought was happening in the drawings.

In Kisumu the aim of the individual interviews was to assess the caregivers' interpretation of the intended messages and to assess about the operational use of the final version of the pictorial medicine instructions and the PATH prototype. The operational use was assessed by asking 'How would you use this tool if you had to advise a neighbour on how to use the Amoxicillin syrup?'. In addition they were asked which instructions leaflet they preferred, the Amoxicillin syrup version or the PATH version and for what reason. During each interview the responses were recorded using a checklist (Appendix X). This checklist listed all the messages that could be identified in the pictorials and provided space for additional notes.

The PATH prototype was pretested for the following reasons: First of all, to provide an insight on how well these pictorials would had been understood if they were to be used in the main study. Secondly, it could provide an insight into whether the different drawing styles really make a difference in understanding the medicine

instructions. The latter could potentially be useful for future recommendations for the use of pictorial aids.

PATH provided a prototype, but they did not communicate which messages they were trying to communicate with the pictorial medicine instructions. To pre-test their prototype for understanding with caregivers, the following messages first had to be identified by the research team:

- The medicine should be given two times a day in the morning and evening
- The medicine should be given for five days
- A child between two months and 12 months should be given one tablet for each dose
- A child between one year to five years should be given two tablets for each dose
- After five days the children are happy
- On day one there is a lot of bacteria and they decrease every day until on the sixth day there are no bacteria
- To prepare the medicine you take out the tablet, put it on a spoon or in a cup, add a little quantity of clean water or breast milk, wait about one minute until it is dissolved and then you give all the liquid to the child.

4.3.3.2 Focus group discussions

One focus group discussion was conducted in Kilifi and one in Kisumu. During both focus group discussions the aim was to assess how the caregivers would use the pictorial medicine instructions to advise each other about the use of Amoxicillin syrup for their children. The participants were also invited to discuss the interpretation of the messages: how the pictorial medicine instructions could be improved and how they could be used in the clinics with the pharmacists.

The focus group discussion that was conducted in Kisumu also discussed the PATH prototype. The aim was to find out how participants would use this prototype to advise each other about the use of Amoxicillin dispersible and to have them discuss the interpretation of the messages. Furthermore, the participants were invited to discuss which pictorial instructions they preferred and for what reason.

4.3.4 Pretesting procedure

Kilifi

In Kilifi I worked together with Isaac Etemezi and Ane was present during the first two rounds of pretesting⁶. In total we conducted five rounds of pretesting interviews over a period of two weeks. The first round was conducted after the first version of the pictorial instructions was developed. Based on that round a new version of the pictorial medicine instruction was developed. During the other rounds the old version and newest version of the pictorial medicine instructions were pretested during one interview. The purpose was to assess which version was better recognized, understood and preferred and thus if the adjustments that were applied to the previous versions were appropriate. After two weeks of interviewing, the focus group discussion was conducted. Based on the inputs of the focus group discussion final adjustments were made to the pictorial medicine instructions.

Kisumu

I trained Lucy Adongo⁶ to conduct the pretesting interviews. We conducted four rounds of pretesting over a period of one week: one round at Kisumu district hospital, one at Nyang'ande and two at Rabuor health centre. During the interviews both the final version of the pictorial medicine instructions and the PATH prototype were pretested. To control for bias of choosing the pictorial instruction you see first as the preferred version, half of the interviews started with the pictorial medicine instructions for the Amoxicillin syrup and the other half with the PATH prototype. After each interview the team analysed the checklist to reflect on the responses of the caregiver and to discuss the findings.

After all the pretesting interviews were conducted, a focus group discussion was held at the home of a caregiver who helped with recruiting mothers for the discussion.

Lucy Adongo was moderating the discussion while Maulyne Aketch⁸ was translating to me.

⁶A more detailed description and reflection on working with the research teams in Kilifi and Kisumu can be found in section 5.7 in the methodology chapter

4.3.5 Data analysis

The analysis of the findings was conducted immediately after each pre-test round and focus group discussion by reflecting upon the responses of the caregivers and upon our own strategy during the interviews. By going through the notes the literal interpretation and the interpretation of meaning could be assessed. The analysis was conducted with the main question in mind: Would caregivers understand the pictorial leaflet when they have to give Amoxicillin syrup to their child and if there would be a problem with understanding how could we adjust this in the pictorial medicine instructions? During analysis of the data from the interviews and focus group discussions in Kisumu additional questions were asked: Would the caregivers understand the PATH prototype when they have to give Amoxicillin dispersible to their child, which of the two pictorial leaflet was better understood and which pictorial leaflet was preferred and for what reason?

4.3.6 Ethical considerations

4.3.6.1 Ethical approvals

Before the individual interviews and focus group discussion were conducted in Kilifi, the project was presented to the MoH Kilifi. The District Minister of Health (DMoH), Dr. Anwar, was supportive of the work, and gave oral permission to conduct the pretesting interviews and focus group discussion at the different clinics in the Kilifi district with the assistance of his staff member, Isaac Etemezi.

While pretesting the pictorial instructions in Kilifi I had conditional approval from the Kenyatta Hospital and University of Nairobi Ethical Research Committee (KNH/UoN-ERC) with recommendations of aspects I had to change in my protocol. I could collect the research permit as soon as I had approval. I delivered the revised research protocol before conducting the pretesting in Kilifi. According to the KNH/UoN-ERC it was allowed to conduct the pretesting interviews and focus group discussion under conditional approval. The MoH in Kilifi accepted this.

In addition, oral permission to use the KCR database from the KEMRI – Wellcome trust programme was obtained from the director of KEMRI Kilifi. Dr. Vicki Marsh had an important role in obtaining this permission from KEMRI by facilitating contact with Prof Charles Mbogo, the director of KEMRI Kilifi.

Before starting pretesting in Kisumu ethical clearance was obtained from KNH/UoN-ERC and I had collected my research permit from the National Council of Science and Technology (NCST).

4.3.6.2 Informed consent and confidentiality

Oral consent was obtained from the caregivers before each individual interview in Kilifi. Written consent was obtained from the caregivers who participated in both focus group discussions and from the caregivers who participated in the individual interviews in Kisumu. The research assistant read the consent forms to the caregivers before the start of each interview or focus group discussion.

4.4 Pretesting findings

This section first describes the pretesting findings from Kilifi. Secondly, it describes the findings from pretesting the final version of the pictorial medicine instructions of the Amoxicillin syrup and the PATH prototype in Kisumu. Finally, it provides a short discussion of the findings.

4.4.1 Pretesting findings Kilifi: From the first version to the final version of the pictorial medicine instructions

This section presents the different versions that were developed and pretested in Kilifi. For each version it describes with how many respondents it was tested, what problems were identified with the literal interpretation and the interpretation of meaning, and what adjustments were applied to the new version.

Version A1

The first version, A1 (figure 8a, 8b & 8c) was tested with three respondents. All three of them recognized one or two objects incorrectly. Two of the respondents identified all the messages in the pictorial instructions as intended. The other respondent misunderstood one message but identified it correctly after she was given a clue.

The following problems were identified with the literal interpretation:

- The mother holding the baby on the front page was either perceived as the mother reading the instruction, the mother checking the head of the baby because it looks dirty or that the mother was giving the medicine to the child.
- One mother described the pneumonia dots as rain.

The following problems were identified with the interpretation of meaning:

- One mother, who described the dots as rain, saw the dots reducing every day, but she did not link it to “pneumonia reducing”. When she was told that the drawing intended to show pneumonia she identified that pneumonia reduces every day you give the medicine.

The following adjustments were made from version A1 to version C⁷:

- The mother who is holding the baby on the front page was modified by removing the handkerchief and by slightly adjusting the mother's facial expression and positioning of her hand. The same drawing on the back page was adjusted in the same way.
- The drawing of "adding water" to prepare the medicine was slightly adjusted. The hands were made more feminine and an arm was attached to the hand because previous studies show that disembodied body parts can be difficult to recognize (Fussell & Haaland, 1976). By adding more body part, an arm, it is more likely for a pictogram to be recognized.
- The colour of the pneumonia dots was changed to red because black dots could be recognized as rain.
- A minimum and maximum age was added to the drawings of the babies for each age group. In case the caregivers are literate they can read the age and are not totally depended on their interpretation of the drawings of the babies. Previous studies support that simple language could help with interpreting pictograms (Houts et al., 2006).
- The measuring cups were made smaller and the babies were made bigger to avoid confusion because in version A1 the cups are the same size as the babies.
- On the back page the sun and moon was added for each day to show that you have to give the medicine three times a day. In version A1 it only shown the sun and midday, which is a conflicting message than what is shown in the table on the inside.
- On the back page a sixth day was added to show that you have to give until the very last dose before all the pneumonia is cured. If all the dots are gone at day five it could potentially lead to confusion and caregivers might think that you can stop giving the medicine on the fifth day.



Figure 10 Adjusted drawing of mother holding baby



Figure 11 Adjusted hands pouring water

⁷ Version A1 was changed to two new versions, B and C. The pictograms on both versions were the same, but the layout was slightly different. The aim was to test which version the caregivers preferred. However, due to limited time and a limited number of participants, version B was not pretested and is thus not presented here.

Version C



Figure 12a. Front page version C



Figure 12b. Back page version C

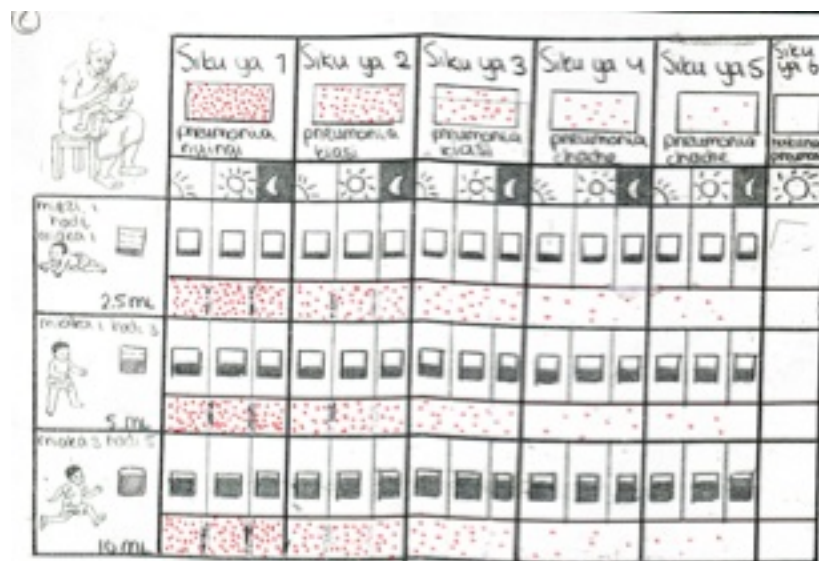


Figure 12c. Inside version C

Version C was tested with nine respondents, three of them could not read. Seven of them recognized all the objects correctly and six respondents interpreted the messages according to the intention of the pictorial medicine instructions.

The following problems were identified with the literal interpretation:

- One respondent described the hands preparing the medicine on the front page as hands holding a jerry can.
- One respondent who could not read described the sun and moon as flowers
- One respondent saw the measuring cups as glasses of water.

The following problems were identified with the interpretation of meaning:

- The caregivers who could not read, could not identify a message that the remaining medicine needs to be poured out after the fifth day. They understood this message when Isaac read it to them.

The following adjustments were made from version C to version D:

- The vertical layout of the front page was changed into a horizontal layout to make it more structured by presenting first what the medicine is for, then how to prepare it and then key messages of how to use the medicine.
- The drawings of the babies to indicate the age in the previous versions were copied from the Lapdap instructions. These could not be used because we did not have legal copyrights, thus new drawings of the babies were made for version D.
- On the sixth day in the treatment course table a drawing of a hand pouring out the remaining medicine was added. This pictorial was also added for the sixth day on the back page, as it became clear from the interviews that many caregivers kept the remaining medicine and used it the next time a child was ill.

Version D



Figure 13a. Front page version D



Figure 13b. Back page version D



Figure 13c. Inside version D

Version D was tested with five respondents. Three of them recognized all the objects correctly and interpreted the messages according to the intention of the pictorial medicine instructions.

The following problems were identified with the literal interpretation:

- One respondent described the drawing of the sun and moon as eyes.
- The same respondent saw the pneumonia dots as blood.
- This respondent and another one saw the measuring cup as the medicine bottle

- These two respondents described the hand pouring out the remaining medicine as a hand pouring out water.

The following problems were identified with the interpretation of meaning:

- The same two respondents did not identify a connection between the pneumonia reducing and the child getting better every day you give the medicine in the pictorial story on the back page.
- One of these two saw the pneumonia dots as blood. After she was told that it intended to show pneumonia, she had difficulties in interpreting the drawing and did not identify that the pneumonia was reducing every day.

The following adjustments were made from version D to version F⁸:

- Version F was a “clean” version, where the text was typed and the tables drawn in a word document and the pictorials are inked instead of pencil drawings.
- On the front page and on the back page a written explanation was added for why the medicine needed to be poured, because it won’t work anymore the next time. In the previous version we had overlooked to include this message.
- Furthermore, the inside was slightly modified by mirroring the babies which were facing away from the medicine in version D otherwise it looks like the babies are running away from the medicine.
- The text “Mwaga!” which is Kiswahili for “pour!” was added under the drawing of the hand pouring out the medicine. This could be a helpful cue for potential users who can read.

⁸ Version D was changed to two new versions, E and F. The pictograms on both versions were the same, but the lay-out was slightly different. The aim was to test which version the caregivers preferred. However, due to limited time and a limited number of participants version E was not pretested and is thus not presented here.

Version F

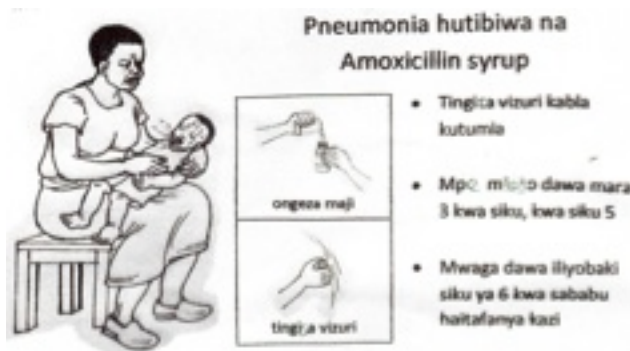


Figure 14a. Front page F



Figure 14b. Back page F

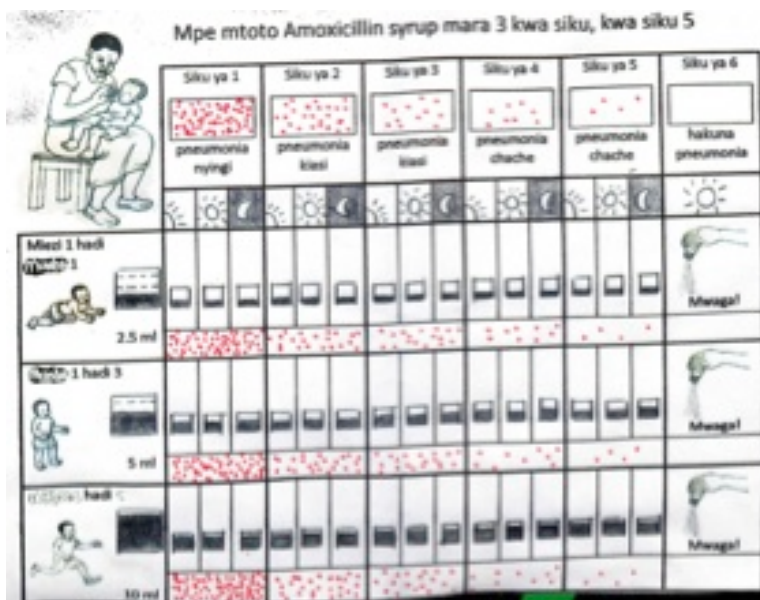


Figure 14c. Inside version F

Version F was tested with six respondents during the focus group discussion. At the start of the discussion two respondents had difficulties with recognizing some of the objects and identifying some of the messages in the pictorial instructions. The other respondents explained to them, and finally all respondents recognized the objects correctly and interpreted the messages according to the intention of the pictorial instructions

The following problems were identified regarding the literal interpretation:

- The measuring cup was recognized by one respondent as the Amoxicillin bottle.
- Two respondents recognized the mother and child pictograms on the back page as it being a different mother and child every day because they have slightly different size.

The following problems were identified regarding the interpretation of meaning:

- Two respondents did not recognize the mother and child on the back as the same mother and child and did not identify the story that the child gets better every day and the mother happier. However, when they were told it intended to show the same mother and child they identified the message of the child getting better every day you give the medicine.
- One caregiver did not make a connection between the pneumonia reducing and the child getting better every day you give the medicine in the pictorial story on the back page. However, she recognized it when another respondent explained it to her.

All the respondents in the focus group discussion could use the tool correctly when explaining the instructions on how to give the Amoxicillin syrup to their neighbour. They agreed with each other that it was important to follow these instructions in order for the child to fully recover and the pneumonia to disappear.

The following adjustments were made from version F to the final version:

- On the front page the text about pouring the medicine was changed to: “pour out the medicine at day 6 because it will not work anymore after it is mixed with water”. This sentence was added to provide caregivers with a reason for why they have to pour out the remaining medicine.
- The drawings of the measuring cups were modified, by making them more similar to the measuring cup that comes with the Amoxicillin bottle.
- On the back a sentence was added telling the caregivers that they should go back to the hospital if their child is not getting better. This was recommended by Dr. Jay Berckley, an experienced clinician working in the paediatric ward in the Coast Province General Hospital, Mombasa. He had experienced many

cases of caregivers who came back to the clinic when the pneumonia has developed to such far stage that treatment is not always able to cure the child anymore.

Final version

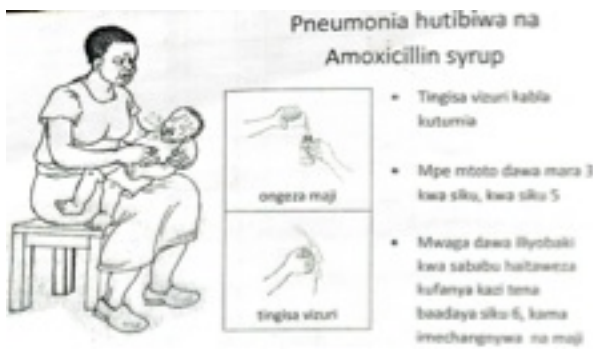


Figure 15a. Front Final version



Figure 15b. Back final

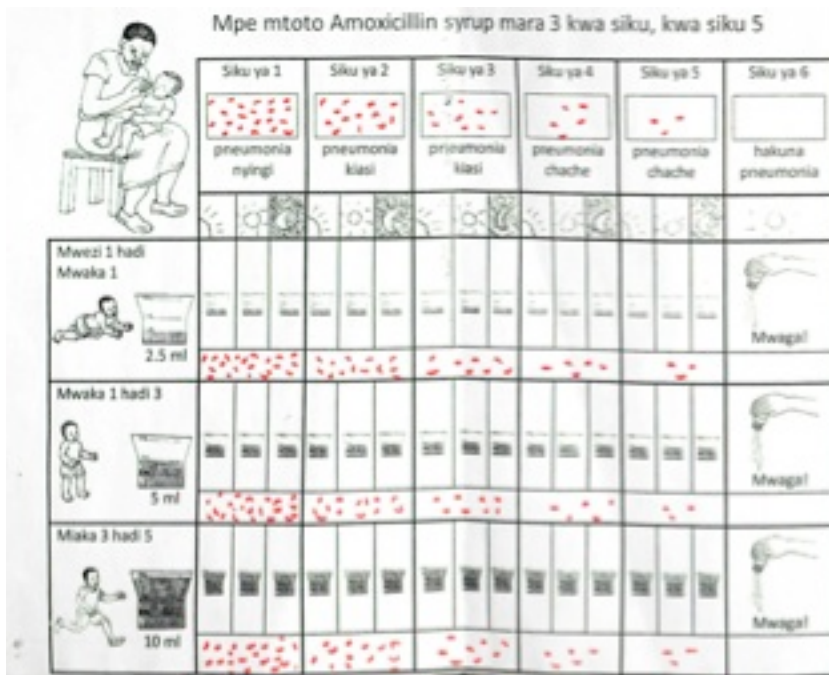


Figure 15c. Inside final version

4.4.2 Pretesting findings Kisumu: Interpretation of meaning and operational use of the pictorial medicine instructions

The final version was pretested in Kisumu with 17 caregivers. They identified the following messages in the pictorial medicine instructions:

The front page:

- All caregivers recognized the child as being sick. Symptoms were described as coughing, having a cold and/or fever. All caregivers described the mothers as being sad, concerned or not happy.
- All caregivers recognized that you have to prepare the syrup by adding water and that you have to shake it well before use.
- The majority of caregivers recognized the message that the medicine has to be given three times a day for five days.
- The majority of caregivers recognized the message that you cannot use the medicine again after it has been mixed with water.

The inside:

- All caregivers recognized the first baby as being between one month and one year at that you have to give 2.5 ml using the measuring cup. Three mothers did not recognize the measuring cup and thought it was either a jerry can or a glass with water, however after they were told that it was intended to show the measuring cup they understood that it was showing the dose to give.
- All caregivers recognized the second baby as being between one year and three years and that you have to give five ml.
- All caregivers recognized the last baby as being between three years and five years and that you have to give 10 ml.
- All but one caregiver recognized the sun and moon as indicating that you should give the medicine early in the morning, during lunch hour and in the evening. One caregiver thought that it was showing eyes, but once she was told that it was intended to show a sun and moon she understood the message that it was indicating the time to give the medicine.
- All but one caregiver recognized that the medicine should be given for five days. One mother thought that it should be given for three days, however she could not point at anything in the pictorial instructions that indicate this.

- The majority of the caregivers recognized that the remaining medicine has to be poured on the sixth day. Three caregivers did not recognize this; one of them did not identify the drawing and could not read the text. The other two recognized that something was being poured but did not link this to the medicine.
- All mothers recognized the dots as showing pneumonia or the disease reducing every day.
- All mothers identified the message that pneumonia or the disease is reducing because you give the medicine

Identified messages on the back page:

- All caregivers recognized that on the first day the child is very sick and that the child gets better every day until the child is recovered on the fifth day.
- All caregivers recognized that the child is getting better because the child receives the medicine.
- All caregivers recognized that on the sixth day you should pour the medicine, because it will expire after it has been mixed with water. Two mothers could not read Kiswahili so they could not read this message, however when they were asked for a reason they said that it had become poison or because it is expired.
- All caregivers recognized the dots as pneumonia or the disease that is reducing.
- All caregivers identified the adherence story and linked that the child recovering and the pneumonia is reducing due to giving the medicine continuously

Operational use

Almost all the caregivers were able to use the pictorial instruction to advise on the correct use of the medicine. They said to prepare you add clean water and shake well. Then you administer the dose according to the age of the child three times a day for five days and the remaining medicine you pour out. One caregiver could not explain for how many days and what dose to give. All but one caregiver recognize that even if the child is feeling better on the third day you should still continue giving because

there is still disease in the body. One caregiver said it was okay to stop giving the medicine if the child is feeling better.

Interpretation and use of the PATH prototype

The respondents identified the following messages in the PATH prototype:

Identified messages about treatment course:

- All caregivers recognized that the sun and moon indicate that you should give the medicine in the morning and evening.
- All caregivers recognized that you should give the medicine for five days
- Half of the caregivers recognized the pictogram showing a mother and child. The other half did not recognize this, most of them perceived it as a person that is not fully drawn yet.
- Most mothers immediately recognized that a child between two months and one year should be given one tablet. However four mothers doubted whether you should give half a tablet because of the clear line in the tablet. Eventually, they all decided that you should give one whole tablet.
- All the caregivers recognized the child between 1 year and 5 years, however 14 of them said that you could not see the age of the child by looking at the pictogram.
- A majority of caregivers recognized the mother with baby at day six as an incomplete human being and the child from one to five years as a complete human being. There were six caregivers who recognized it as the same children as the one with the dose but now they were happy or healed.
- Almost all mothers recognized the dots as the bacteria reducing as you give the medicine, however one caregiver thought it was the dose to give that is reducing every day.

Identified messages about preparation:

- All the caregivers recognized that you have to take the tablet out of the pack
- All caregivers recognize that you have to put the tablet on a spoon
- The majority of caregivers identified that you should add water to the tablet, however four caregivers could not identify the drop of water.

- Ten of the caregivers thought that the clock was indicating the time you should give the medicine to the child. You give around 9 in the morning and around 9 at night. The other seven described it as a clock that shows you that you have to wait to give the medicine.
- Nine caregivers recognized the final pictogram as showing that you give the medicine to the child. The other eight caregivers found it difficult recognize the face and either described it as a biscuit or a round with holes.

All caregivers would administer the medicine two times a day for five days and picked the right dose according to the age of the child. Nine of the caregivers said they would prepare the medicine by taking a pill out the pack, put it on the spoon, add water, wait to dissolve and then give it. The other eight thought you should administer the tablet with some water and were not aware that it was a dispersible tablet. They were shown the Coartem dispersible which they were familiar with; at that point they changed their mind and said they would put the tablet on a spoon, mix with water and then give. Ten of them did not say that they would wait for the tablet to dissolve. Most caregivers said they would continue giving until the fifth day even though the child was looking fine at the third day because there is still some disease in the body. Three caregivers said it was okay to stop giving if the child is feeling better. All these three caregivers saw the PATH prototype first and the pictorial medicine instructions for the Amoxicillin syrup second.

Comparison in understanding and preference between the pictorial medicine instructions for the Amoxicillin syrup and the PATH prototype

When the caregivers were asked which version they preferred, the majority explained they preferred the Amoxicillin syrup instructions because these pictograms are more clear, and you can easily see what is happening and what you need to do. The mother and the child look like real mothers and children, and the caregivers said they resembled them. Furthermore, they said the PATH prototype was difficult to recognize and five caregivers said that if they showed it to their mother, they would not understand.

The adherence story in the pictorial medicine instructions for the Amoxicillin syrup was a main reason for many caregivers to prefer these instructions. Twelve caregivers

listed this as the reason, because you see what you need to do and at the same time you see in the instructions how the child is getting strong and healthy and how the disease disappears when you are giving the medicine.

Four caregivers preferred the dispersible because the leaflet was more simple, contained less information, and they thought the sun and the moon were more clearly shown. Another reason that three of them preferred the PATH prototype was because the instructions were written in English, and they understood English better than Kiswahili.

4.5 Discussion of pretesting findings

The findings show that it is important to pre-test pictorial medicine instructions with their potential users. The first version of the instructions was quite well understood, as it was based on instructions that were already extensively pretested. However, small adjustments to each version made the pictorial medicine instructions easier to recognize and to understand.

The majority of the respondents had been to school and had a relatively high education level. There were only three mothers in Kisumu who said that they could not read. They had no big difficulties in understanding the pictorial instructions, but none of them recognized the sun and moon as eyes and since they could not read none of them could identify a reason why to pour out the medicine. It would have been better to pre-test the pictorial instructions with mainly mothers with low or no education. If caregivers who cannot read understand the pictorial instructions, it is likely that caregivers who can read will understand them as well. However, if caregivers who can read understand the pictorial instructions, it does not necessarily mean that caregivers who cannot read understand these instructions. Therefore, there is a possibility that when the pictorial medicine instructions are used for the main study they are more difficult to understand and use by caregivers who cannot read.

It is unclear whether the caregivers will pour out the remaining medicine when following the pictorial medicine instructions. There is a pictogram displaying a hand pouring out the remaining medicine, but the reason for why you have to pour is

written on the instructions leaflet. The findings show that the mothers who could not read overlooked this message. If the caregivers do not know that the medicine loses its strength after it has been mixed with water, then it is possible that they will not pour out the remaining medicine because they think that you can use it again.

The final version of the pictorial medicine instructions was well understood by the respondents in Kisumu. Furthermore, the caregivers gave correct advice on how to administer the Amoxicillin syrup to a neighbour's child using the pictorial medicine instructions. The PATH prototype was understood by most caregivers, however there were some difficulties in identifying the pictograms of the mother and the children and with understanding all steps of the preparation process. This supports findings from previous studies (Fussell & Haaland, 1976; Houts et al., 2006) that abstract pictograms are more difficult to recognize. The caregivers gave correct instructions regarding the use of the dispersible using the pictorial medicine instructions, however not all caregivers advised the correct way of preparing the medicine.

The abstract pictograms used in the PATH prototype did not only create some confusion, it was also the reason why the majority of the caregivers preferred the pictorials of the Amoxicillin syrup over the PATH prototype; the pictorials for the Amoxicillin syrup are more clear and the respondents said they could relate to them. They felt that they could identify themselves with the pictograms. It is unknown whether this preference would make an actual difference in how the caregivers would use the pictorial medicine instructions when taking their medicine.

Finally, the findings show that the pictorial medicine instructions for the Amoxicillin syrup were well recognized and understood. In addition, the respondents could use them to advise a neighbour on how to administer the treatment. The main study will assess if and how the pictorial medicine instructions will actually be used when caregivers administer Amoxicillin syrup to their child and if they pictorial instructions have any influence to adherence.

5. Research Design

This chapter describes the research methodology based on the inquiry and the theoretical framework of the study. At first it describes this theoretical framework and how it influenced the methodology. Secondly, the time frame of the fieldwork is presented followed by a detailed description of the research setting, the study sample and the data collection procedure and methodology. Finally the research methodology is reflected upon and discussed by giving a detailed description about working with the research assistants and their influence on the project, my own reflexivity, the process of analysing the data, strengths and limitations of the research design and the ethical considerations of this project.

5.1 Theoretical Framework

A theoretical framework is important for a study to be coherent throughout the different phases. It will help to decide how to plan, conduct, analyse and present a project (Malterud, 2001). Knowledge will not arise from empirical data alone but from the combination of this data and the theoretical framework the researcher is using. Defining your inquiry paradigm is what sets the theoretical framework and thus what can guide you through the research process. A paradigm responds to three questions (Guba, 1990):

1. The ontological question: What is the nature of reality?
2. The epistemological question: What is knowledge?
3. The methodological question: How do you go about finding out knowledge?

This thesis is driven by a constructivist paradigm. This paradigm looks at the ontological question from a relativism viewpoint. Relativism acknowledges that a world exists independent of the human mind, but that reality is always perceived through a mental framework. This mental framework is shaped by experiences and thus differs between persons (Guba, 1990). Knowledge is perceived as a human construction; if realities exist in the minds of people than interaction seems to be the only way to access these realities (Guba, 1990). This means that the researcher has a role in how knowledge is shaped, and thus the term “I” will be used in this study.

Using “I” to address the researcher clearly shows that the researcher’s eyes were used as a tool for this study (Patton, 2002).

In line with this paradigm and the research question asked, a qualitative research methodology was found to be most appropriate to explore why caregivers administer the Amoxicillin syrup the way they do and if and how receiving pictorial medicine instructions have an influence on this. Kvale (1996, p.27) supports this justification of using a qualitative methodology to understand the perspectives of the caregivers on medicine use and the usefulness of pictorial instructions: “The purpose of the qualitative research [...] is to understand themes of the lived daily world from the subjects’ own perspectives”.

Furthermore, the study design was based on a phenomenological approach. A phenomenological approach is based on phenomenology, which is the study of how things appear to the subject being studied (Kvale & Brinkmann, 2009; Malterud, 2012). The aim is to try to understand and describe the experiences of the research subjects through their own perceptions. In order to achieve this you have to be open to their perceptions and therefore be aware and critical to your own preconceptions (Kvale & Brinkmann, 2009). Reflexivity is an on-going process where researchers reflect upon their own understanding and their influence on the research (Malterud, 2001), and was used as a tool to be aware and critical to my own understanding throughout the entire study process (see section 5.8).

The data were analysed based on this phenomenological approach by using Malterud’s (2012) model of systematic text condensation (STC). This model uses thematic coding as a way to analyse data. The advantage of analysing by thematic coding is that it is accessible or relatively easy to use for researchers with little experience in conducting qualitative research (Robson, 2011), as this was the first time I conducted qualitative study this model was seen as appropriate to analyse the data.

The STC model is a four-step process of analysing the data based on Giorgi’s phenomenological methodology for analysing data (Malterud, 2012). The four steps of STC that were used for the analysis are:

1. Total impression – From chaos to themes
2. Identifying and sorting meaning units – from themes to codes
3. Condensation – from code to meaning
4. Synthesizing – from condensations to descriptions and concepts

A more detailed description of how these steps were followed during my analysis can be found in section 5.9.

5.2 Time Frame

The study was conducted within the following time frame:

April – July 2013	Planning stage; writing the research proposal establish contacts in Kenya, apply for ethical research proposal in both Norway and Kenya and apply for the research permit in Kenya
13 June 2013	Project approval from Ethical research committee in Norway
28 September – 15 October 2013	Formative research
17 October 2013	Conditional approval from research committee in Kenya and conditional research permit
21 October – 7 November	Development and pretesting of pictorial instructions in Kilifi
30 October	Project approval from Ethical research committee in Kenya and research permit
12 November – 17 November	Pretesting pictorial instructions in Kisumu
19 November – 25 January 2014	Data collection period through interviews, observations and focus group discussions
13 February – 25 August 2014	Analysis and writing the master thesis

5.3 Study site

The formative research was conducted at five different clinics in the Kisumu area, in one rural clinic, one semi-urban clinic, two smaller urban clinics and Kisumu district Hospital. The fieldwork was conducted at two of those five clinics: At Rabuor Health Centre, the semi-urban clinic, and Nyang'ande dispensary, the rural clinic, because it

was expected that it would be more likely in (semi) rural areas to find caregivers who are illiterate and for whom the pictorials could therefore influence more how treatment is given.

Rabuor health centre is located directly next to the Kisumu – Nairobi road and thus easily accessible. Because of its relative closeness and accessibility to Kisumu City the area is perceived to be semi-urban. The Health Centre is a medium size centre, with many visitors and long waiting lines every day. It provides services such as out patient care, maternal care, HIV and TB treatment, assistance with delivery, and has several wards. The pharmacy was a small room and the pharmacists talked to the patients through a small window with bars in front of it.

Nyang'ande dispensary is located in a rural area and was a relatively small and simple dispensary. Regardless of its small size there were a lot of patients every day, however the waiting line was not as long as experienced at the Rabuor Health Centre. Services that were provided were out patient care, maternal care, HIV and TB treatment and assistance with delivery. There were no official wards, however there were some extra beds in case a mother had to wait to deliver her baby. The pharmacy was a consultation room where the pharmacist sat down the patients when giving out the medicines and instructions.

The other three clinics where formative research was conducted were located within Kisumu city. Kisumu district Hospital was a public hospital in the centre of Kisumu city. There were many visitors and long waiting lines. It provided all services that can be expected from a public hospital in a developing country. The pharmacy was well staffed, with 14 pharmacists at work. The pharmacists communicated with the patients through a big window and often two pharmacists were helping the patients while the other pharmacists were packing medicine and taking care of administration. The other two smaller urban clinics were Lumumba Health Centre and the Railway Dispensary. Lumumba Health Centre was bigger than Railway Dispensary and had collaboration with Faces, an organization that focus on HIV prevention, treatment and counselling, and was in close contact with the KEMRI-CDC research programme. The pharmacy was a counselling room where the pharmacists sat down with the patient as they gave the medicine and the instructions.

Railway dispensary was a small, relatively quiet, clinic with few visitors and few services. The pharmacists communicated with the patients through a small window with bars.

The first days of formative research all the clinics were out of Amoxicillin syrup and in most clinics it had already been out of stock for two weeks. After three days the clinics got a delivery with new medicines. Throughout data collection all clinics faced problems with medicines being out of stock. Amoxicillin syrup, which came with the delivery in the beginning of October, was available at all the clinics during data collection.

Interviews were carried out at the caregivers' homes and they all lived within the areas around Rabuor Health Centre and Nyang'ande dispensary. The majority of the houses were accessible by motorbike and some by foot only. Both focus group discussions were carried out at the home of one caregiver who lived between Rabuor and Nyang'ande which was relatively central for all the participants of the group discussions.

5.4 Study sample

This section describes the sampling strategy and the two different sample groups for this study: Caregivers of children younger than five years who were diagnosed with pneumonia and prescribed Amoxicillin syrup, and the pharmacists working at the clinics.

5.4.1 Sampling strategy

All the participants of this project were selected with the purpose of learning from them in order to obtain in-depth information about the research questions. This is purposive-sampling (Malterud, 2001; Patton, 2002), a sampling method that is often used in qualitative studies with the aim to gain in-depth understanding about the phenomenon you are researching.

5.4.2 Caregivers of children younger than five years who were diagnosed with pneumonia and prescribed Amoxicillin syrup

The main targets of this study were caregivers of children younger than five years who were diagnosed with pneumonia and prescribed Amoxicillin syrup in the clinic. The caregivers were recruited at the clinic if they matched these criteria. We asked their permission for a follow-up interview after they received the Amoxicillin syrup together with the pictorial medicine instructions at the pharmacy of the clinic.

In total 27 caregivers were interviewed for this study.⁹ Almost all caregivers were mothers, with the exception of one grandmother, one sister and one father. All caregivers had some schooling, the majority up to class 8 in primary school. The majority of them were housewives, small private business entrepreneurs or both. Most of them lived with their extended families, where the parents shared their piece of land with their sons, daughter-in laws and grandchildren. However, some owned their own piece of land or were renting a small place on someone else's land.

5.4.3 Pharmacists working at the clinics

In order to obtain an understanding of the perspectives of the pharmacists about how medicine instructions should be given and the potential usefulness of the pictorial medicine instructions, individual interviews were held with the pharmacists working at both clinics. Three of them were females and one was a male.

5.5 Data collection procedure

Before the start of data collection the final version of the pictorial medicine instructions were discussed with the pharmacists to ensure that they were familiar with the contents of the pictorial instructions. The pharmacists were requested to provide the pictorial medicine instructions with the Amoxicillin syrup when a child younger than five years was diagnosed with the pneumonia. The aim was to use a naturalistic approach (Patton, 2002), and not to manipulate the research setting by giving the pharmacists a script of what instructions they should give. We noticed after 10 observations that the caregivers did not give any information about the pictorial

⁹ In total 35 caregivers were recruited. However 6 of them had no phone and we could not find their home with the directions that they had given us. The other two caregivers cancelled the interview because one caregiver had to travel to attend a funeral and the other caregiver was busy.

medicine instructions at all, and we decided at that point to request the pharmacists to say that the pictorial medicine are about the Amoxicillin syrup and that they could help the caregiver with administering the medicine.

While the pharmacist was giving out the Amoxicillin syrup and the pictorial medicine instructions the research assistant was present in the pharmacy to observe communication between the pharmacist and the caregiver. After each observation she left the pharmacy and we took the caregiver aside. We asked if we could visit them at their home after a week to talk about how their child was feeling. If the caregiver agreed we wrote down their contact details and visited them the following week.

During the home visit we explained what an interview was and read the consent form to them. If the caregiver agreed to participate, we conducted an in-depth interview about how the child was doing now, how treatment was given, for what reason, their understanding of the pictorial medicine instructions, whether they had used the pictorials and if so if they were helpful and in what way. After the interview we left our contact details with the caregiver.

Half way through the data collection period we contacted most of the caregivers whom we had interviewed to participate in a focus group discussion. Caregivers who had no phone and who lived too far away for us to go there just to invite them were not invited. We conducted two different focus group discussions, one with caregivers who used the pictorial medicine instructions and one with caregivers who did not use them.

At the end of the data collection we conducted structured interviews with the pharmacists working at the clinics in which we shared the preliminary findings and invited them to reflect upon these findings.

5.6 Data collection methods

This section describes the different data collection methods used in the study: opportunistic observations and informal interviews and conversations, structured observations, semi-structured in-depth interviews, focus group discussions and structured interviews.

5.6.1 Opportunistic observations and informal interviews and conversations

The first three weeks of fieldwork were used for opportunistic observations and informal interviews and conversations with the aim to learn about the research setting. Topics that were explored were every day life at the clinics, the health care system, and how the staff communicated with the patients. In addition, the aim was to gather knowledge about the Amoxicillin syrup necessary for the development of the pictorial medicine instructions. Finally, informal observations were conducted at the pharmacies in order to develop a checklist for the structured observations during later data collection.

Almost every day of these first three weeks was spent at one of the five different clinics. During these visits, I was taken notice of things that were happening, talked with the pharmacists and other health providers at the clinics and wrote all my experiences in a field diary. Furthermore, I talked with local contacts from KEMRI and the MoH in Kisumu and with my research assistant and with other local contacts to explore the culture, language, every day life and health topics of my new setting.

5.6.2 Observation

Structured observations were conducted at the pharmacy where the caregivers received the Amoxicillin syrup and instructions from the pharmacists with the aim to explore communication between pharmacists and caregivers. Observation is an appropriate method to gain an insight into the social interaction between pharmacists and caregivers, and to assess to what extent reported behaviour from the pharmacists and caregivers about communication corresponds with actual behaviour (Kielmann, Cataldo & Seeley, 2011).

A checklist was used during the observations, to provide structure and consistency (Appendix 7). The focus of the observations was to explore what exact instructions the pharmacists gave to the caregivers about the Amoxicillin syrup regarding preparation, dosage, number of day to give, pouring out the remaining medicine and information about the pictorial medicine instructions.

In total we conducted 35 observations, 15 at Nyang'ande dispensary and 20 at Rabuor Health Centre. One research assistant conducted all observations. During the first four I was observing as well and afterwards we shared our observations, filled in the checklist and reflected upon what we had seen and heard in order for the research assistant to learn what to focus on during the observations. That only the research assistant should be present at subsequent observations was a conscious decision to influence the setting as little as possible; the presence of one observer probably influences the setting less than two, especially if the second one is a foreigner. After each observation the research assistant filled in the checklist and discussed her observations with me. The checklist was filled in after the observation and not meanwhile. Crossing off a checklist while observing would influence the behaviour of the pharmacists and caregivers, and the aim was to have as little attention on the observer as possible.

5.6.3 Semi-structured interviews with the caregivers

Semi-structured in-depth interviews were conducted at the homes of the caregivers, to assess how treatment was given, for what reason treatment was given the way it was, understanding of the Amoxicillin treatment instructions, perception of usefulness of the pictorial medicine instructions, and experience of communication with the pharmacists. Semi-structured interviews are conversations with a structure and purpose with the aim to gain an insight into the perspectives of the interviewee. The researcher controls the conversations and introduces the topic, asks open questions and follows up on the interviewee's answers (Kvale, 1996; Patton, 2002). The interviews were based on a question guide. The guide used for the first six interviews was slightly adjusted based on reflection on new themes and questions that arose during those six interviews (Appendix 8 and 9).

Before each interview the caregivers were asked if the seating arrangement was comfortable for them to speak. Furthermore, before reading the consent form and conducting the interview we conducted small talk with the caregivers such as how their day had been, with the purpose to establish an atmosphere in which the caregiver would feel free to speak his or her mind.

All caregivers were interviewed once, and each interview lasted between 40 and a 100 minutes. All interviews were tape-recorded and I took notes of the translations and non-verbal cues in a notebook during the interview. At the end of each interview we made sure we talked with the caregivers about some easy, daily life topic to ensure we left them with a positive feeling. We also gave them a soap bar to show our appreciation.

5.6.4 Focus group discussions

Two focus group discussions were conducted with the aim to elaborate on preliminary findings from the interviews, by letting the caregivers discuss amongst each other for what reason they administered the Amoxicillin syrup the way they did and their perceptions on the usefulness of pictorial medicine instructions (appendix 10 & 11). This method was chosen because a focus group discussion, a formative way of having people discuss certain topics with each other, can be useful to provide extra information and deepen the research findings (Dawson, Manderson & Tallo, 1993; Morgan & Krueger, 1993).

Half way during data collection it was found that half of the caregivers had used the pictorial medicine instructions when giving the Amoxicillin syrup and the other half of the caregivers had not use the pictorial medicine instructions. To deepen the findings, as well to create a comfortable and open setting for all caregivers we chose to conduct one focus group discussion with caregivers who had used the pictorial medicine instructions and one with caregivers who had not used them.

Five caregivers who used the pictorial medicine instructions participated in the focus group discussion and four caregivers who had not use them participated in the discussion. Both discussions lasted approximately 90 minutes. Maulyne was the moderator and Lucy was translating. This enabled me to follow the discussion, take notes and ask questions in case I had some. During the focus group discussions we provided sodas, and travel costs were reimbursed. The caregiver at whose home we conducted the focus group discussion received a bag of sugar, flour and the leftover sodas as appreciation gift.

5.6.5 Discussion of preliminary findings with pharmacists

At the end of the fieldwork period we conducted structured interviews with the pharmacists to share the main preliminary findings from the observations and the interviews and asked for their reflections on the findings. Topics were instructions caregivers received, how caregivers experienced the communication of the instructions, how caregivers gave the Amoxicillin syrup, and the influence the pictorial medicine instructions had on this when the caregivers had used these.

The topics were written in a guide (appendix 12), and the aim was to have the pharmacists discuss these reflections amongst each other. However due to time and logistic constraints, the findings were shared with each pharmacist's separately in an unstructured interview instead of a group discussion. Interviews were conducted with three of the pharmacists¹⁰ and lasted between 30 and 50 minutes.

5.7 Working with a research team

My experience of working with an experienced research team in Kilifi was the foundation of how I trained my research assistants in Kisumu. Therefore, this section first describes the process of working with a research team in Kilifi and then the process of training and working with a research team in Kisumu.

5.7.1 Kilifi

In Kilifi I worked together with Isaac Etemezi and Ane Haaland. Isaac has lived in Kilifi for many years, is fluent in Kiswahili and works for the MoH in Kilifi. He was trained in pretesting skills by Ane in the past, had experience with conducting pre-test interviews on visual instructions for malaria medicines and with moderating focus group discussions. Ane had been leading numerous projects in development and pretesting of pictorial communication materials and medicine instructions, several of them with Kilifi as a base.

Working with Isaac and Ane enabled me to strengthen my own research skills. From Isaac I learned how to ask open questions during a pre-test interview. Secondly I experienced how it is to work with someone who is a research partner. Isaac has an interest in communicating with pictorial materials and his past experience with

¹⁰ One of the pharmacists who worked at Nyang'ande clinic had gone on leave during the last two weeks of data collection, so we could not share the preliminary findings with him.

conducting pre-test interviews enabled for a working relationship in which he conducted the interviews and I listened to short translations, took notes, asked questions and probed when necessary. After each interview we discussed the information that the respondent had given us. Because of our different backgrounds we noticed different aspects during the interviews, and these observations complemented each other. This experience taught me that working with a research partner can deepen and strengthen the research findings.

From Ane I learned how to improve my research skills through experience-based learning. Boud, Keogh and Walker (1985) describe experience-based learning as a three phased cyclic process: Preparation, actual experience and processing of what has been experienced. In practice this meant that for each round of pretesting interviews and focus group discussion I prepared by defining the aims of the interviews or focus group discussion and by defining my own role and skills required. After preparation I went to the field to conduct the interviews and focus group discussion. Then, after each round of pretesting, I reflected upon the fieldwork by answering questions such as ‘what went well during the interviews and what was not so good?’, ‘What have I learned?’ and ‘What could I do better next time?’.

I prepared the first round of pretesting with help from Ane, and then Ane conducted the interviews together with Isaac as I observed and took notes. Afterwards we reflected upon what I had learned from observation. The second round I prepared based on the learning from the first round and I conducted the interviews together with Isaac while Ane took notes. Afterwards we reflected on the results, what I had learned, and I received constructive feedback on my interview techniques from Ane. I became aware that I had to ask more probing questions and that I had to take more control during the interviews. During the first interviews I let Isaac conduct them as I was listening. However, I had to become more active and guide Isaac in what aspects to focus on and what questions to ask to be able to meet the aims of the interview. By continuously being reflective I learned how to conduct good quality pretesting interviews, how to probe and how to be in control during interviews while Isaac was conducting the interviews.

Finally, Ane's direct involvement in the development and pretesting in the pictorials creates a potential bias on how she evaluated and commented on chapter four of the thesis. Therefore Dr. Vicki Marsh, a medical doctor and social scientist, who has experience with developing and pretesting pictorial communication materials through conducting research in collaboration with Ane and who has been working and living in Kilifi for more than 20 years, commented on the chapter before the thesis work was submitted.

5.7.2 Kisumu

Process of finding an assistant

During the formative research and when pretesting the pictorial medicine instructions in Kisumu I worked with Lucy Adongo who was recommended as a research assistant by Dr. Titus Kwambai, the DMOH in Kisumu. Lucy is a young woman who grew up in Kisumu and speaks Kiswahili, English and Dholuo the local language spoken in Kisumu. She has a diploma in adult education, has been working as a translator and transcriber for qualitative research projects and was saving money to start an undergraduate degree in Public Health.

Lucy got offered another Job at the beginning of November. Her new job was a permanent position and better paid, so we agreed that it would be of her best interest to start working for her new employer from the last week of November. Lucy conducted the interviews and was the moderator during the focus group discussion when we pretested the pictorial instructions in Kisumu. She continued being involved in my project by helping with transcribing throughout the whole data collection period, but I had to find a new assistant for the main data collection.

Lucy recommended me to work together with Maulyne Aketch. They had worked together in the past as transcribers and translators on several projects. Maulyne had transcribed focus group discussions for Dr. Kwambai, who agreed with Lucy's recommendation. Maulyne had past experience with conducting interviews for a qualitative study. She had a diploma in administration, lived in Kisumu, grew up in an area within the Kisumu district, and spoke Dholuo, Kiswahili and English. Being a mother of two young children she could also relate to the caregivers in the study.

Training and working with the research assistants

My aim of training and working with the research assistants was for them to develop skills that enabled them to be partners who were interested and engaged in my project, rather than “just” being translators. With Lucy I had an extensive training period of three weeks during the formative research. We conducted unstructured observations at the clinics and discussed our impressions afterwards. We interviewed the health providers together and practiced qualitative interviewing skills such as asking open questions and follow up questions. We discussed the methodology and terminology of the project and brainstormed about the messages and outline of the pictorial medicine instructions. These three weeks were essential to establish a good working relationship for the pretesting period.

After the development and pretesting of the pictorial instructions in Kilifi I spent one day with Lucy practicing pretesting interviews prior to conducting the actual pretesting interviews. During this day I first demonstrated Lucy how to conduct a pre-test interviews by pretesting the pictorial medicine instructions with her. Then Lucy practiced her pretesting skills by interviewing me about the instructions. Afterwards we reflected on what went well and what she could improve. That same day we went to Railway dispensary clinic where she practiced the pretesting interviews with three caregivers. During these interviews she translated her questions and the caregivers’ answers to me and I took notes. After each interview we discussed the quality of the interview and how to approach the next one. This enabled her to improve her skills with each interview. The experienced-based learning approach was used throughout the whole week in which we conducted the pre-test interviews and focus group discussion.

Because of time constraints my training period with Maulyne was much shorter than the one with Lucy. Maulyne became involved in the project the last week of November by translating during the focus group discussion for pretesting the pictorial medicine instructions in Kisumu. The following day we discussed the aims of my project, the methodology and terminology, and went through the observation guide and interview guide for the pre-test interviews so that she had an overview of the aims of the project and the different data collection methods. We started with the structured observations the day after. During the first observations both Maulyne and I were

present at the pharmacy. After each observation we discussed what we saw and heard, what I would like Maulyne to focus on and we filled in the observation checklist together.

While we were at the clinics to conduct the structured observations and recruit participants the aim was to conduct more pre-test interviews. I let Maulyne lead the first interview and translate her questions to me. Maulyne had told me she had been conducting qualitative interviews before, however during the first interview I noticed that she was used to interviewing with a structured questionnaire and she asked many leading questions. Afterwards we discussed the different interview styles and Maulyne was open to constructive feedback and motivated to improve her skills. I decided to let her conduct pretesting interviews as a training method to improve her skills for the in-depth interviews. The interviews used for training were not analysed for the purpose of this study.

I also used the experienced based learning approach to train Maulyne, while we practice interviewing by conducting pre-test interviews and also while conducting the main interviews of the study. Before each interview we discussed the aim of the interviews and how to ask open questions and follow up questions. Maulyne conducted the interviews and translated summaries to me, as I took notes and asked follow up questions when necessary. After the interviews we reflected upon how Maulyne and I communicated together, how she asked questions and if there were any questions that were left unanswered.

We reflected while walking, because walking can reduce a status difference between people and makes receiving critical feedback less threatening compared to sitting down together to talk. During those talks Maulyne immediately brought up points about her strengths and weaknesses during the interview. Because all the interviews were tape-recorded we could listen back to parts of the tape, often Maulyne hears she had asked a leading question or missed out on a probe and corrected herself. In most cases we conducted two interviews in one day and Maulyne could practice her learning immediately after reflection.

The first four interviews contained a lot of leading questions, however Maulyne was improving with each interview she conducted. After the first four interviews, the subsequent interviews were of good quality, with open questions, probes and valuable information from the caregivers during the interviews. Furthermore, Maulyne's interest, motivation and confidence increased during the fieldwork period. We discussed findings from the interviews together, which was important to understand the information from the interviews from a cultural perspective. Altogether, through experience based learning Maulyne developed and improved her research skills and became a valuable research assistant for the project.

Influence of the research assistants on the study

Both Maulyne and Lucy had an influence on the findings of the study. Because they transcribed and translated the interviews there was a risk that their interpretations and perceptions would affect the translations. In order to minimize this influence as much as possible they translated the interviews verbatim and directly from Dholuo to English so that I could read the story of the caregiver as they told it. The interpretations of certain words or expressions were discussed after I had read the transcripts. Furthermore, Maulyne and Lucy discussed the translations amongst each other, ensuring that the translation was as correct as possible. However, for none of us English was the first language, and thus there is a risk translations could be interpreted differently than it was told by the caregivers.

Since Maulyne was the one conducting the interviews, there was a risk of her perceptions or interpretations influencing the way she translated during the interviews. We tried to minimize this by making sure that we had the same of understanding of the terminology used in the interviews. Meaning of words or phrases such as adherence or finishing a full course were discussed before conducting the interviews so that it could be translated into words with the same meaning in Dholuo. Secondly, we often discussed the importance of being open to the caregivers' story and setting preconceptions aside when we enter the homes of the caregivers. Furthermore, we reflected together upon what was said by the caregiver, the body language during the interview and other things we observed in and around the homes of the caregivers.

Maulyne was good at creating a trusting and comforting atmosphere during the interviews, and I could notice that the caregivers trusted her and felt open to talk because of their open body language. Often she talked a bit about her baby before the start of the interview. Informing them about being a mother herself seemed to create a level of understanding between the caregivers and Maulyne. An example that shows that Maulyne created a comforting atmosphere are the first four interviews of the main study that she conducted with the caregivers. She asked many leading questions, however instead of answering yes or no the caregivers gave information and contradicted her when they did not agree with her question. Therefore, even though the first interviews were of relatively poor quality we still got a lot of valuable information and the interviews could be used for analysis. The following is part of the transcription of caregiver C, where she contradicted Maulyne during the interview:

'M: So you see, my children like the medicine because it is so sweet. So they sometimes find it and drink it you know, did that happen to you?'

Caregiver C: No mama. I put it when the children cannot find it [...] You know, you should not let them drink the medicine'

I have discussed the project to a great extent with both Maulyne and Lucy and also daily observations were discussed throughout the fieldwork. Their perceptions and understanding influenced my own attitudes and perceptions in the research setting. However, this was most likely favourable for understanding the findings within the context in which the research was conducted. An example is that some caregivers had been to primary school, and could read Dholuo but not Kiswahili. From my research assistants I learned that the classes in primary school are overcrowded and that some students might not learn to read in school because they get too little supervision. However, they often learn to read Dholuo by the bible during church, which is written in Dholuo.

5.8 Reflexivity

In qualitative research the researcher is actively involved in gathering data and has an influence on the findings. The researcher should be reflective and critically examine this influence (Malterud, 2012). I tried to be reflective of my own influence and how I learned new knowledge during the fieldwork phase by constantly reflecting on how I

gained new insights and by keeping a field diary in which I wrote my experiences at the end of every day. This diary was not only a helpful tool to get an overview of my own learning, but also to get an insight into my own prejudices, emotions, perceptions and understanding that I experienced during the field work period.

Being a foreigner in the research setting

I am a young woman from the Netherlands. I had never travelled to Kenya before, although I had lived in South Africa for eight months and I had been travelling around in Botswana, Namibia, Mozambique and Zimbabwe. Kenya was a new setting for me, but I found it quite easy to adapt since certain aspects were comparable to my previous experiences in an African setting. These were aspects such as being a young white woman in an African context, how to move around by public transport and how to deal with administrative bureaucracies in order to obtain visas and permits.

Even though certain aspects were comparable to those countries I had been living and travelling to before, there were also many cultural aspects that were new to me. I learned a lot about the Luo culture by walking around with my research assistants. During these walks we discussed all the things we observed along the route. This is how I learned from which plants you can make cotton or how the housing arrangement on a plot of land is connected to the structure of the family living there. In addition, with both the research assistants and with the pharmacists who participated in my project I shared stories of our daily life and upbringing. This helped me to understand aspects such as the importance of religion, wife inheritance or the role of women in society. It is impossible to fully comprehend a new setting and culture within a couple of months, however by being open-minded and by asking many questions during those walks and conversations I tried to learn as much about the setting and culture as possible.

Finally, I noticed that some caregivers had expectations because I am white and from a presumably rich. Several times the caregivers asked after an interview if I could help them with financial matters such as school or treatment fees. Maulyne's response to these questions was that I was visiting for the purpose of conducting my study and that I did not have the funds to support them. The caregivers accepted this and said they understood this. Even though we made sure we read the consent form and

explained the purpose of the visit before conducting the interview, the expectation of receiving some money for participating could possibly have led some of the caregivers to agree to a home visit for an interview at the first place.

The influence of my educational background

I have an education background in social Psychology and International Community Health. Because of this background I have a great interest in health behaviour, learning and motivation and in communication between health providers and patients. These are all aspects within the topic of my thesis and I conducted an extensive literature search to expand my knowledge. Furthermore, the topic fits within my education background therefore I already had many theories around my research question and objectives before going to the field. This created certain expectations and preconceptions that I had to be aware of.

A way of dealing with this, beside keeping a field diary and trying to understand my own learning in the field, was to have the constructivist paradigm as a theoretical basis for the research. By using this paradigm I had to acknowledge that knowledge is always a human and social construction and that everybody constructs their own understanding and knowledge of the world. This approach made me critical to my own understanding, and during the interviews I was open to hear the information from the perspective of the caregiver. However, during the first interview I realized that I had more pre-conceptions than I had been aware of. I was surprised to discover that caregiver A had not read the pictorial instructions. I realized that I had expectations based on the literature search and the pretesting: In the articles about the influence of pictorial medicine instructions on understanding and adherence it was not mentioned that there were any participants who did not use the pictorials and during pretesting the pictorials instructions of this study were well understood. I think for these reasons I developed the expectation that it would be a very useful tool for the caregivers and I did not really consider the option that the caregivers would not use the instructions. This experience made me aware to be more critical towards my assumptions during all the subsequent interviews.

Finally, because of my background in social psychology I felt confident in training my research assistants and in being reflective myself. I have learned many

motivational, communication and learning theories and reflection was a relevant skill during my bachelor degree. These competences are vital in conducting qualitative research and had a positive influence on my own learning as a researcher and the outcome of the project.

Working in a clinic setting

Not only the Kenyan culture was new to me but also being in a clinic setting. Before coming to Kenya my only experience of health clinics was visiting my general practitioner as a patient in the Netherlands. I believe that this enabled me to understand the clinic setting without too many preconceptions about the medical treatment and standard from a health professional point of view. However, I had certain expectations on how a doctor should communicate with their patients, based on my experience of being a patient myself and from the master programme in International Community Health. At the clinics I was aware of these expectations and tried to focus on the communication between the health providers and patients without being critical on how I think they should communicate according to my own experience.

My educational background also influenced how the health providers and the caregivers perceived me. I established a good relationship with the pharmacists that I worked with. However, at the same time I had the feeling that they were very critical towards my project and they were not always handing out the pictorial instructions when a caregiver matched the recruitment criteria. This could have happened because the pictorial medicine instructions implied that I was criticizing their way of giving instructions, and secondly because it was me who was asking them to give out the pictorials; a 23 year “young” woman, from a different country with a different culture, with no background in the medical sector.

On the other hand, I experienced that many of the caregivers felt free to discuss a health topic with me because I was not a health professional. Since we recruited the caregivers at the clinics, there was a possibility that the caregivers saw us as being connected to these clinics. However, during the introduction of the interview we emphasized that we were not connected in any way to the clinic and that I was a student with no background in medicine. I experienced the caregivers to be open

about their use of medicine, about communication with the pharmacists and in how they described their experiences at the clinic.

5.9 Data analysis

This section describes the different steps related to the data analysis.

5.9.1 Field notes and transcriptions

Immediately after the interviews and focus group discussion notes and reflections that were written down were summarized in a word document. All the interviews and focus group discussions with the caregivers were tape-recorded and the research assistants transcribed and translated these recordings. The interviews with the pharmacists were conducted in English and were transcribed by me.

The tape recordings were transcribed as soon as possible after completion of the interviews. This gave the opportunity to reflect upon our interview technique as well as the themes we addressed and questions we were asking. This led to an adaption of the interview-guide and to an improvement of the interview skills by focusing more on probing techniques. Furthermore, going through the transcriptions was a good basis to develop a guide of themes to address for the focus group discussions. Almost all the transcriptions were completed within the fieldwork period; the research assistants sent three transcripts that were not completed through email after completion.

5.9.2 Steps of Analysis

The interviews were analysed according to Malterud's STC model (Malterud, 2012) that is described in the first section of this chapter. The first step, getting an overview of the content of the data, was partly done in the field and partly when returning back to Oslo. Transcriptions were read over and over while taking reflective notes to achieve a proper overview of all the data.

Colour coding the transcriptions based on their thematic meaning, was conducted as the next step. Themes were chosen based on the objectives in order to answer the questions. The themes used were; how treatment was given, for what reason treatment

was given this way, the pictorial medicine instructions and experience of communication with the pharmacist.

The following step was to divide the codes into different categories or sub-themes. These categories were chosen inductively and deductively based on the objectives and topics the caregivers addressed during the interviews. Examples of categories were *past experience* or *perceptions on pictorials*. Half of the caregivers used the pictorial instructions and half of the caregivers did not use them when giving Amoxicillin syrup to their child. This naturally created two groups of caregivers with similar demographics (appendix 13). Therefore, during this step it was decided to analyse the two groups separately and compare and contrast the findings. Furthermore, at this stage the transcripts of the focus group discussions were analysed by looking in what way they supported or contradicted the findings and whether new findings emerged based on the objectives.

In the last step of analysis the different categories are synthesized into a meaningful whole. The data were written in a narrative form, the findings chapter of this thesis.

5.10 Discussion of Methodology

According to Mays and Pope (2000) a qualitative methodology can be judged by looking at its validity and relevance. The term validity is mostly used in quantitative studies, where you question the truth of your findings. Since this study has a constructivist approach and the reality is not seen as a factual truth, it is more appropriate to discuss the trustworthiness instead of the validity. Trustworthiness is the qualitative term of validity and means whether the findings are worth paying attention to (Malterud, 2011). Malterud (2001) proposes to describe the following three factors to discuss the different aspects contributing to trustworthiness:

1. Reflexivity, “An attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process” (Malterud, 2001, p.484).
2. Transferability, “The range and limitations for application of the study findings, beyond the context in which the study was done” (Malterud, 2001,

p.481).

3. Interpretation and analysis, a detailed description of the theoretical framework and of the procedure of analysis.

Transferability means whether the findings can be generalized beyond the setting. The study sample and a detailed description of the methodology can increase the transferability (Mays & Pope, 2000). The data collection methodology and procedure are described in detail in this chapter. The study sample was purposive; caregivers of children under five years who were diagnosed with pneumonia and prescribed Amoxicillin syrup were selected because the pictorial medicine instructions were developed for the Amoxicillin syrup with the message that it treats pneumonia. This sample was small, and recruited at two clinics in a small geographical area. Therefore, the results cannot be generalized to other settings. However, the pictorial medicine instructions were pretested in Kilifi as well and the results show that they were well understood and liked by the respondents. This indicates that caregivers in other parts of Kenya could also understand the intentions of the pictorial instructions.

This chapter described the reflexivity, the theoretical framework and the analysis of the data in detail in this chapter, which increases the trustworthiness of this study. Furthermore, this project used different data collection methods to broaden the understanding of the findings; this enabled to answer the research question based on information from different sources. According to Mays and Pope (2000) triangulation is a way to strengthen trustworthiness, by ensuring understanding and encouraging reflexivity in the analysis. An example of how triangulation contributed to the trustworthiness of the findings is that during the interviews the caregivers often recalled the oral instructions from the pharmacists differently than what we recorded during the observation. In addition, the pharmacists gave different information about the Amoxicillin syrup to the caregivers than they had told us. Therefore, if structured observations at the pharmacy were not conducted the findings about communication of the medicine instructions would be based on perceptions of the caregivers and the pharmacists, and not reflect how the instructions were actually given.

The relevance of the methodology depends on its transferability, which has already been discussed above, and on whether it this methodology can provide new knowledge (Mays & Pope, 2000). This study provides new knowledge by answering

the research gap identified in the literature. To my best knowledge, there was no information available that a study on the influence of pictorial medicine instructions using a qualitative methodology had been done before. Furthermore, in the previous studies on pictorial instructions research assistants or trained assistants handed out the pictorial instructions together with verbal instructions on how to give the medicine (Dowse & Ehlers, 2005; Ngoh & Shepherd, 1997; Yin et al., 2008). This study was conducted in a setting as naturalistic as possible without additional communication about the Amoxicillin instructions, thus it provides insight in how pictorial medicine instructions would be used when they come as an insert with Amoxicillin syrup.

The following strengths and limitations of the research design should also be taken into account when evaluating the this study:

Strengths:

- The pictorial medicine instructions were carefully developed and the final version of the pictorial medicine instructions was pretested with the caregivers for understanding in Kisumu before they were used in the study. Therefore it was highly likely that the caregivers in the study would understand the pictorial instructions.
- The pictorial medicine instructions for the Amoxicillin syrup were based on pictorial medicine instructions for Lapdap (chlorproguanil-dapsone) and Coartem (artemether – lumefantrine), both had been pretested with caregivers and health providers in Kenya until they were well understood. Thus the pictorial medicine instructions for this study had a strong possibility to be well understood by the caregivers.
- The presence of the supervisor during the development and pretesting of the pictorial instructions in Kilifi enabled me to learn from her. Learning from the supervisor's experience in developing and pretesting pictorials and receiving constructive feedback improved both the quality of the pictorial instructions and my research skills. Dr. Marsh gave feedback on chapter four of this thesis to control for the supervisor's potential bias on this process.
- I was an independent researcher¹¹, and therefore I could report the findings

¹¹ I received a small grant from the Ivar Helle's Foundation (appendix 22). However, funding was given without any expectations, rules or restrictions.

- without meeting expectations from collaborating institutions or organizations.
- I was responsible for the whole research process, from the planning phase to writing up this master thesis. This created nearness to the field and the ability to improve research skills and thus the quality the research project.

Limitations:

- There could be an observer bias because I developed the pictorial medicine instructions that were used in the study and I believed in the usefulness of these instructions.
- The observations might have influence communication between the pharmacists and the caregivers.
- Time and resources in the field limited data collection.
- Even though copies of the pictorial medicine instructions were provided to the MoH in Kilifi and Kisumu after data collection, there is no guarantee that this will lead to any direct benefit for caregivers or pharmacists at the clinics.

5.11 Ethical considerations

This section describes the ethical approvals and permissions as well as the ethical considerations of the informed consent, confidentiality and beneficence and usefulness of the project.

5.11.1 Ethical approvals and research permit

Ethical approval was obtained from REK (Appendix 14) and from KNH/UoN-ERC (Appendix 15). A positive assessment of the project was received from the Norwegian Social Science Data Service (NSD) (Appendix 16). Furthermore, permission from NCST to carry out the research in Kenya was obtained (Appendix 17).

5.11.2 Informed consent

In guideline 4 of CIOMS (The Council for International Organizations of Medical Sciences, 2002) informed consent is defined as: “a decision to participate in research, taken by a competent individual who has received the necessary information; who has adequately understood the information; and who, after considering the information, has arrived at a decision without having been subjected to coercion, undue influence or inducement, or intimidation”.

Permission was obtained from the MoH, Dr. Kwambai, to conduct the study at different clinics within the Kisumu district. The persons in charge at the clinics gave verbal consent to conduct the research at the clinics after reading the letter from Dr. Kwambai introducing my study and after I explained the purpose and methodology.

The pharmacists were informed about the study objectives and they all consented with participating. They were asked if they would be willing to hand out the pictorial instructions and were asked for oral permission to observe them while they give out the instructions. At the end of data collection we informed them about the preliminary findings from both the interviews and the observations.

The caregivers were not asked for their consent during the observation. I decided this because of a practical reason, asking for their consent meant that we had to get them out of the queue when it was finally their turn at the pharmacy and by doing so we would also disturb the work of the pharmacists. Secondly we did not ask for their consent because by informing them that they are observed we created the risk that the caregivers could be distracted while they receive the medicine from the pharmacists and therefore would not be able to focus on the instructions.

When the caregivers were recruited at the clinics, we did not tell them the complete purpose of the home-visit. If we had told them the objectives of the study this could have influenced the way they gave the Amoxicillin syrup and they way used the pictorial instructions. For this reason we choose to fully inform them at their homes, by reading the consent form before conducting the interview. The research assistant read the consent form to each caregiver, so in case the caregiver could not read we would be sure s/he would know the information in the form. The language of the consent form includes some terms that are quite technical, such as confidentiality, because it had to be written according to the guidelines of the KNH/UoN-ERC. Therefore, the research assistant also explained the purpose of the interview in a more informal way to make sure all aspects were clear. After reading the form and explaining the purpose of our visit we gave them some time to process the information and encouraged them to ask any question they had before we started the interview. The same procedure of informing the caregivers and obtaining consent was used for the focus group discussions.

The consent forms were first written in English and were translated in both Dholuo and Kiswahili. During the interviews and the focus group discussions we made sure we had the forms in all the three language versions with us, so the caregiver could chose which language s/he preferred. The English consent forms for the interviews and focus group discussion can be found in the Appendix (17 & 18).

5.11.4 Confidentiality

The caregivers' names were replaced with a code, such as Caregiver A, B or C, directly after the interview to respect their anonymity. The pharmacists were also given a code, such as Pharmacists A, B or C, however due to the small sample and their unique position full anonymity cannot be guaranteed. This has been explained to the pharmacists and they gave their consent.

In the field the tape recording and transcriptions were saved on an external hard drive and kept together with the field notes and observation checklists in a locked closet to which only I had access. When returning to Oslo they were stored in a locked suitcase. The research assistants worked on their own computer while transcribing. As soon as they handed over a completed transcription to me they deleted that transcription and corresponding tape recording from their computer.

Preliminary findings from the interviews with the caregivers were shared with the pharmacists. To ensure confidentiality and anonymity we talked about general findings and did not at any point refer to specific information that a certain caregiver had shared, nor did we mention the names or the houses of the caregivers. The pharmacists were part of the recruitment process by handing out the pictorial instructions, however due to the large amount of patients they see every day it is highly unlikely that they remembered the caregivers we talked to.

The topic of confidentiality and anonymity was discussed with both research assistants prior to data collection. Both of them have been assisting in research projects before, and these concepts were already well understood by them. Both assistants signed a contract stating that they agreed and understood the terms of confidentiality and anonymity.

5.11.5 Risks and Benefits of the research project

There were no direct risks to the health care providers or the caregivers from participating in the study. However, during the observation the health providers might have experienced some distress because the assistant was observing what s/he is doing. There were ways to minimize this risk; it was ensured that the pharmacists felt comfortable and well informed about the presence of the researcher and the assistant, and only the assistant was observing in the majority of the observations.

During the interviews conscious awareness and reflection was used to prevent the caregivers from any harm. The caregivers could have experience some stress when describing how and why they administered the Amoxicillin syrup, whether they had used the pictorial medicine instructions and how they understood the pictorials. During the focus group discussion there was special attention on the interaction between the caregivers. Homogenous groups were created, caregivers who used the pictorial medicine instructions were in a different group than caregivers who did not use the pictorial instructions, to minimize the risk that the caregivers who did not use the pictorials could feel “guilty” for not using these. Additionally the issue of privacy and confidentiality was emphasized in the written informed consent as well as in the oral introduction at the start of the discussion.

A potential benefit for the caregivers is that most of them gained understanding in the treatment instructions of Amoxicillin syrup and in the importance of adherence. Another benefit is that this project provides an insight into how treatment instructions are given at the pharmacy, how caregivers give an antibiotic treatment, factors that influenced caregivers to give the medicine the way they did and how pictograms could help the caregivers with understanding and following the treatment instructions. This insight could potentially be helpful for future interventions, such as for organizations focusing on how to improve adherence to medicine instructions.

6. Research findings

This chapter describes the research findings from the observations, the interviews and the focus group discussions. During the interviews it was found that 13 of the participants used the pictorial medicine instructions when giving treatment to their child and 14 of the participants did not use these instructions. In this chapter the findings from both groups will be described, compared and contrasted.

Firstly, it is described which treatment course of Amoxicillin syrup the caregivers gave to their child. Secondly the different reasons caregivers explained for why they administered the treatment in the way they did are described with several sub-themes. The final section describes the caregivers' perceptions of the pictorial medicine instructions.

6.1 The way the caregivers administered the Amoxicillin syrup

During the interviews the caregivers explained the treatment course they administer to the child: the dose, how many times a day, for how many days and what they did with the remaining medicine in case there was some left. In the analysis these treatment actions were classified as either correct or incorrect, according to the Amoxicillin treatment guideline.¹² For example, a caregiver who gave her child of four months a dose of 10 millilitres has given an incorrect dose. These correct and incorrect actions are summarized in table 3. A more detailed overview of the actions from each of the caregivers can be found in the appendix (20).

Table 3. Caregivers' correct and incorrect actions in giving the treatment course

		Dose	3 times a day	5 days	Treatment regime	Treatment course	Pour
Caregivers who used the pictorial medicine instructions	Incorrect actions	1	0	2	2	2	2
	Correct actions	12	13	11	11	11	11
Caregivers who did not use the pictorial medicine instructions	Incorrect actions	10	1	11	11	14	2
	Correct actions	4	13	3	3	0	12

¹² The instructions of Amoxicillin syrup described in section 3.5, *Amoxicillin syrup to treat childhood pneumonia*.

There is a clear difference in the treatment course administered by the caregivers who did not read the pictorial medicine instructions compared to the caregivers who read them. Almost all caregivers who read the pictorial instructions gave a correct treatment course. One child started vomiting heavily after each dose so her caregiver thought she might be allergic to the drug and stopped the treatment; this reaction might have been cause because the caregiver gave a too high dose to the child. The other caregiver administered Amoxicillin incorrectly due to external factors. Her child was prescribed a ten-millilitre dose, which makes it impossible for the caregivers to give for five days because there is not enough syrup in the bottle.¹³

In contrast, none of the caregivers who did not read the pictorial medicine instructions gave Amoxicillin syrup according to the correct treatment instructions. Many caregivers gave a too high or low dose for age and administered the syrup for the wrong number of days, either until the medicine got finished or until the child was feeling better. Furthermore, two caregivers treated two children at the same time with the same bottle of Amoxicillin syrup and had no syrup left after two or three days. None of them were aware that they had been administering a wrong treatment course.

Finally, the majority of the caregivers who had read the pictorial instructions said that there was still some syrup left in the bottle after five days but that they had poured it out and two caregivers kept the remaining. In contrast, the majority of caregivers who did not use the pictorials explained that they gave all the syrup but if something had been left they would have kept it.

6.2 Reasons explained by caregivers for the way they administered the Amoxicillin syrup

The caregivers provided three reasons for why they administered treatment the way they did: Pharmacists' instructions, past experience and incorrect understanding of the Amoxicillin treatment instructions. The caregivers who read the pictorial medicine instructions explained that the pictorials was one of the main reason why they gave

¹³ There is 100 ml Amoxicillin syrup in the bottle. When a child is prescribed a 10 ml dose it is not possible to give the full treatment course (10x3x5 = 150 ml)

the treatment the way they did, thus the pictorial medicine instructions are described as a fourth reason.

6.2.1 Influence of the pharmacist’s instructions about the use of the Amoxicillin syrup on treatment course

Many caregivers were influenced by the pharmacists’ instructions when they gave the Amoxicillin syrup. This section describes the treatment instructions that the pharmacist explained to the caregivers when handing out the Amoxicillin syrup. Secondly, it describes how the caregivers recall these instructions. Finally it describes what influence the pharmacist’s instruction had on how the caregivers administered the Amoxicillin syrup.

6.2.1.1 The pharmacists’ oral instructions about the use of Amoxicillin syrup as they were observed

None of the caregivers received full and detailed information about the Amoxicillin instructions from the pharmacists, regardless of the clinic or the pharmacist working at that moment. The observation checklists are summarized in Table 4, which shows how many caregivers received information about different parts of the treatment instructions, such as treatment dose and treatment regime, from the pharmacists. A more detailed overview of the instructions that the pharmacist gave to each caregiver can be found in the appendix (21).

Table 4. Number of caregivers received information about the treatment course from the pharmacists

	Written 1x3	Preparation	Demonstrated preparation	Oral 1x3	Dose	5 days	Finish course	Pour	Pictorials
# caregivers who used the pictorial medicine instructions (n=13)	13	11	3	4	5	2	4	0	8
# caregivers who did not use the pictorial medicine instructions (n=14)	14	10	4	5	5	2	5	0	8

The pharmacists wrote 1x3 for all the caregivers to indicate that they should administer the syrup three times a day. In most cases, while writing this down they explained that the medicine should be prepared by adding clean water up to the level indicated on the bottle and that it should be shaken well before use.

In some cases the pharmacists provided additional information, such as oral instructions that the medicine should be administered three times a day or what dose the caregivers should give to their child. Furthermore, when the pharmacists explained the treatment dose they more often referred to tea- or tablespoons instead of the measuring cup that comes with the bottle.

Only some caregivers were instructed give the medicine for five days. More often the pharmacists instructed that caregivers should finish the full course and did not specify what they meant by that. None of the caregivers were instructed to pour out the remaining medicine. In two cases the pharmacists asked the caregivers if they knew how to use the medicine, when the caregivers confirmed this the pharmacists wrote 1x3 on the package and gave the medicine without giving further instructions.

All caregivers received the pictorial medicine instructions from the pharmacists. About half of the caregivers in each group received some information about the pictorial instructions. The pharmacists either said that the pictorials were explaining the Amoxicillin instructions, that they could help with administering the medicine, or both.

6.2.1.2 The pharmacist's oral instructions about the use of Amoxicillin syrup as they were recalled by the caregivers

The majority of the caregivers recalled the pharmacist giving them more information about the Amoxicillin instructions than what they actually received. Table 5 shows how many caregivers recalled receiving information about different parts of the treatment instructions, such as treatment dose and treatment regime, from the pharmacists. A typical example is a caregiver who was told by the pharmacist to add water up to the mark indicated on the bottle and then shake the medicine, and 1x3 was written for her on the bottle. However, she recalled the instructions she got from the pharmacist the following way:

"I was told to boil water and then there is a mark that it should reach, so I mix the medicine with the water and then I shake. Then she told me to give three times a day ,morning lunch hour and evening, a teaspoon full." (Caregiver W)

Table 5. Number of caregivers that recalled parts of the instructions about the treatment course from the pharmacists

	Written 1x3	Preparation	Demonstrated preparation	Oral 1x3	Dose	5 days	Finish course	Pour	Pictorials
# caregivers who used the pictorial medicine instructions (n=13)	13	13	7	9	8	11	1	4	11
# caregivers who did not use the pictorial medicine instructions (n=14)	14	13	8	7	9	1	9	0	2

There are some differences between caregivers who followed the pictorial instructions and caregivers who did not follow these instructions regarding what information they recalled. Caregivers who used the pictorial instructions more often remembered receiving information about the pictorial instructions and that they should give the medicine for five days compared to what the pharmacists actually told them. Furthermore, the pharmacists more often instructed to finish the course than what was remembered by these caregivers. An example is the following caregiver who did not get any information about the pictorial medicine instructions. When asked what the pharmacist instructed her to do, she answered:

“The pharmacist told me to boil water and then add to the level and shake. She wrote for me to give 3 times. [...] She told me to give for five days. [...] And then there was this paper instructions about how to give the medicine that she told me to go and read first.” (Caregiver Z)

In contrast, caregivers who did not use the pictorial medicine instructions less often recalled receiving information about the pictorials and more often remembered receiving information about finishing the full treatment course compared to what the pharmacists actually told them.

Furthermore, the caregivers who used the pictorial medicine instructions all remembered the pharmacists’ instructions according to the Amoxicillin treatment

guidelines. In contrast, many of the caregivers who did not use pictorial instructions recalled the pharmacists providing them with incorrect treatment instructions.

Not all caregivers remembered receiving more instructions than what the pharmacists provided. There were some caregivers who remembered the instructions as the pharmacist told them. For example, the pharmacist asked one caregiver if she knew how to use the medicine. The caregiver confirmed this and the pharmacist wrote 1x3 on the medicine package, gave the Amoxicillin and did not provide any further information. During the interview this caregiver recalled:

"She gave me all those drugs and she ask me that "you know how to prepare it? You know its being done?" I told her that I knew so she just gave me. And she wrote me 1x3 for the Amoxyl. [...] That's all that she instructed me to do." (Caregiver L)

Even though the caregivers often remembered obtaining more information than the pharmacist provided them, none of the caregivers recalled receiving complete treatment instructions from the pharmacists. Furthermore, caregivers were critical towards the information they get at the health facilities and said that the pharmacist gives too little information about how to give the medicine and that you often go home not really knowing what to do.

"When I go to the window there [...] the way she handle me on how I am going to use this drug, I think if they add something there it could be good. [...] So you know if she tells me one times three, I don't know what that one times three means, so how they handle the sick and how she explains to you, they should improve." (Caregiver C)

6.2.1.3 Influence of the pharmacist's instructions on how the caregivers gave the Amoxicillin syrup

Nine caregivers who used the pictorial medicine instructions and ten caregivers who did not use the pictorials explained they gave the Amoxicillin syrup according to the pharmacists' instructions. This meant that they prepared the medicine, gave a certain dose or gave for three times a day because the pharmacist instructed them to do so. However, since none of the caregivers recalled the pharmacists giving them complete instructions, no caregivers gave the complete treatment course based on the pharmacists' instructions.

Caregivers who used the pictorial medicine instructions recalled the pharmacists instructing them about the correct treatment course and thus following the pharmacists' instructions lead to giving the Amoxicillin according to the treatment guideline. In contrast, the pharmacists' instructions as they were recalled by the caregivers who did not use the pictorial instructions was often incorrect, which lead to giving a wrong dose for the child age or for a wrong number of days.

Furthermore, caregivers who did not use the pictorial instructions sometimes misinterpreted the instructions from the pharmacists. An example is a caregiver for whom the pharmacists wrote 1x3 on the medicine pack to indicate that she should administer the medicine three times a day. The caregiver thought this meant she had to give the medicine for three days.

"I gave for three days, I thought that was the dose that was written for me that I had it finish. [...] It was written 1x3. And then I gave three times a day because the doctor had told me to." (Caregiver P)

Another example is two caregivers who were instructed to finish the full course. Both administered the Amoxicillin syrup until it got finished because that is when they thought they had completed the full treatment course.

"The doctor told me that if what I told him was true the medicine that he prescribed was going to help me. So I gave it the way the pharmacist told me because she knows how this medicine should be used and I wanted my child to get better. The pharmacist told to boil water, add till the mark and then give 3 times a day 2.5ml until I finish the course. [...] The medicine got finished after 1,5 week, that is when I finished the course." (Caregiver R)

6.2.1.4 The pharmacists' response to the preliminary findings of the observations

At the end of the data collection period we shared the preliminary findings from the observations with the pharmacists and requested them to reflect upon it. Two pharmacists denied at first that they provide incomplete instructions to the caregivers.

The other pharmacist explained there was no time to give a full explanation, because the queue of patients is always so long and they are already waiting for a long time.

At some point all three pharmacists explained that often they do not give complete instructions because most caregivers come regularly and used Amoxicillin syrup before, so they expected them to know what to do.

“You know, the majority of these clients have used Amoxyl before, it is not the first time they use it. So when you ask, our first question is to ask if they have used this drug? Then you ask do you know how to reconstitute it? So such a client you just give a brief explanation. But then if it is a client who has never used, and when is using for the first time that is when you have to explain, that you have to shake well. So if they have used that it probably when we don't really give explanation for some.”

(Pharmacist B)

All the pharmacists thought that the caregivers should receive better instructions for them to give Amoxicillin syrup in the correct way. However, they also explained that they probably do not have the time to explain better, that caregivers might not listen to you, or that caregivers will not understand the instructions.

“You know most of the clients are illiterate, so majority will not understand. Even if you tell them this drug is supposed to be used for five days or not more than one week hmm... some will extend, some will give even less than five days. Some can even extend more than one week, which is not good. So with that situation it is quite challenging.” (Pharmacist A)

6.2.2 Influence of past experiences with giving or taking medicines that influenced how the caregivers gave the Amoxicillin syrup

During the interviews caregivers talked about two past experiences that influenced how they administered the Amoxicillin syrup: learning about treatment adherence and using Amoxicillin syrup before. These are described in this section.

6.2.2.1 Influence of learning about completing a full treatment course on how caregivers gave the Amoxicillin syrup

During the interviews many caregivers said they completed the full treatment course. They had learned about the importance in the past from experiences with taking medication, visiting the clinics and communication with health workers. Table 6 displays the number of caregivers that learned about the importance of completing a full treatment course in the past.

Table 6. Number of caregivers that learned about the importance of completing a treatment course in the past

	Learned by doing wrong	Learned during ARV clinic day	Learned by being told
Caregivers who used the pictorial medicine instructions (n=13)	5	2	2
Caregivers who did not use the pictorial medicine instructions (n=14)	1	1	3

There were more caregivers that followed the pictorial medicine instructions who explained they learned about the importance of completing a full treatment course in the past than caregivers who did not follow these instructions. The majority of the caregivers who read the pictorial instructions learned this by giving or taking a wrong treatment course in the past. They stopped giving a medicine when the child was feeling better, or they had stopped taking a medicine themselves when they were feeling better. The disease reappeared after a week or two, often even more seriously than before.

"I just learn it by myself, in the past. When I was still in school, I feared medicine, even if I went to the hospital and I was given malaria drug, mostly I feared the malaria drugs, so nowadays I can take them, but then I took them and when I felt better they next day I threw them away, but after two or three days I got seriously sick." (Caregiver S)

When they returned to the clinic the doctors quarrelled with them and explained to them that the disease had re-occurred because they had not completed the treatment course. This is how they learned about the importance of completing a treatment course.

So when I was taken to the hospital I had to be in the ward, and then the doctors quarrel with me and told me that I didn't take the medicine well, that is why the disease is back. So I asked the doctor why he is saying the disease is very serious. He told me that when you are taking medication, and you don't take the next day, those bacteria had tasted the medicine and you don't give them the next day, they will wake up lots of them because now they are used to the drug.” (Caregiver S)

In contrast there was only one caregiver who did not use the pictorial medicine instructions that shared a similar experience. Other caregivers learned about the importance of finishing a full treatment course in the past from a doctor during a visit at the clinic or by being on ARV treatment. Both clinics have specific days for patients who are on ARV treatment where they discuss topics such as drug adherence. Caregivers who did not learn from experience but from being told did not know the reason why they have to take the full treatment course. They explained they completed the Amoxicillin treatment course ‘because that is what the doctors tells you to do’.

There is a difference in how knowledge about completing a full treatment course influenced the caregivers in the way they administered the Amoxicillin syrup. The caregivers who read the pictorial medicine instructions all said that they administered it for five days, because that is when you have completed the full treatment course. On the other hand, the caregivers who did not read the instructions either gave until all the medicine got finished or until the child was better because that is when they thought that you have finished the full course.

6.2.2.2 Influence of past experiences with administering Amoxicillin syrup on how treatment was given

All but two caregivers had used Amoxicillin before. During the interviews many of them explained at some point that they administered the syrup as they had been doing before. This was more often the case for caregivers who did not use the pictorial medicine instructions compared to caregivers who used the instructions. Table 5 shows how many caregivers prepared or gave the medicine the same way as they did in the past.

Table 5. Number of caregivers prepared or administered the Amoxicillin syrup the same as in the past

	Preparation	Dose	3 times a day	Days
# Caregivers who used the pictorial medicine instructions (n=13)	7	1	2	1
# Caregivers who did not use the pictorial medicine instructions (n=14)	6	4	7	6

In both group many caregivers prepared the medicine the same way as they did in the past, which was according to the Amoxicillin treatment guidelines.

“I knew how to prepare because I used Amoxicillin for the other child before. You see, you first boil water, then you leave it to cool, then there is this mark and you fill it and then I shook it. (Caregiver N)”

Furthermore, caregivers who did not read the pictorial medicine instructions often reported they gave a certain dose, for three times a day and for a certain number of days because that is how they administered the Amoxicillin syrup before. All caregivers gave the same dose as they did in the past gave a wrong dose for the age of the child. In addition, four of the caregivers who administered the syrup for the same number of days as they did in the past administered syrup for a wrong number of days.

“I just gave it as I gave it in the past. I mixed Amoxyl with boiled water up [..]. I just left the medicine to cool and then shook it and then I gave her. I gave her one spoon, the big one, for almost a week, because that is what I did the last time I gave. I see if the cough is over before the week is finished, then I stop, and if it is still there I go back.” (Caregiver I, child is 4 months, she ended up giving for three days then the cough was over)

In contrast, caregivers who read the pictorial medicine instructions less often administered the Amoxicillin syrup as they did in the past and if they did they gave the syrup according to the correct treatment instructions.

6.2.3 Influence of incorrect understanding of the Amoxicillin treatment instructions on how caregivers administered the Amoxicillin syrup

During the interviews many caregivers who did not read the pictorial medicine instruction shared incorrect understandings about correct use the Amoxicillin syrup: they said they were afraid to overdose their child and about re-using the remaining Amoxicillin syrup the next time a child is sick. In contrast, only two caregivers who used the pictorial instructions talked about re-using the medicine and none of them talked about overdosing their child.

All caregivers who kept the remaining Amoxicillin syrup did this in order to use it again the next time their child is sick. Furthermore, eight of the caregivers who did not read the pictorial medicine instructions explained that if some syrup had remained they would have kept the medicine to use it again.

"You know I stopped giving the medicine when he was feeling better. [...] He was not coughing anymore so I stopped giving at the fourth day. I didn't know if I saw a real change, or that the cough was just lying to me that it is not there. [...] If the cough is lying then the next day or week you might see the child coughing again and then you have poured out the medicine. So the child is coughing again, and you have no medicine because you poured it. That is why it's better to keep the medicine. (Caregiver W)"

Some caregivers who did not follow the pictorial medicine instructions were afraid to overdose their child, which led to giving an incorrect Amoxicillin treatment course. Three of them explained that you should stop giving the medicine when the child was feeling better, because then the disease is cured and otherwise you might overdose your child.

Another caregiver gave it two times a day instead of three to not overdose her child.

"I gave two times, because she is young and the strength of the medicine was a lot, so I only gave in the morning and in the evening. I thought that if I give her three times I might give her too much (Caregiver R)"

Furthermore, one caregiver gave a smaller dose in order to not overdose her child.

”If I give a full cup I will overdose, so I only gave half. [...] I gave her that way because, you see the child is not so big yet, she is still small, so I think that I should not give her too much of the medicine otherwise I might overdose. (Caregiver Y)”

6.2.4 Influence of the pictorial medicine instructions on how caregivers administered the Amoxicillin syrup

The caregivers who read the pictorial medicine instructions described three ways in which the instructions influenced the way they administered the Amoxicillin syrup. Two caregivers explained that the pictorial medicine instructions were a reminder of what they already knew about giving the medicine and that it encouraged them to give it according to the instructions because you see how the disease reduces every day and how the child is recovering every day. They had already learned how the bacteria reduces in the past, but seeing it visually encouraged them to continue the treatment.

”I Think those people wrote it to me like a reminder, on how the prepare the medicine and how to give. And then it shows the level of the disease on the first day, the second day and so on until it’s finished on the fifth day. And you see the child getting better (the drawn child). [...] That paper encourages, even if you wanted to stop giving the child the medicine, you see that there is still disease. (Caregiver X)”

Secondly, for eight caregivers the pictorial medicine instructions confirmed some things they already knew about the Amoxicillin instructions, but it also helped them with some of the things they did not know yet such as which dose to administer, for how many days and that you have to pour the medicine after treatment is completed.

”I followed the instructions of the doctor and when I looked at the picture, I was told on how to give the child the drug, so when I came I read it and I combined with the one the doctor told me. [...] For example the doctor did not tell me how much I should give, but from the paper I saw I had to give 5ml. [...]” (Caregiver J)

Two of those eight caregivers explained they learned from the pictorial instructions that they should not skip a dose but should give the full treatment course for all the disease to disappear. Three other caregivers said they felt encouraged to give the entire treatment thanks to the way it was drawn how the disease reduces every day.

Finally, three caregivers explained they only followed the pictorial medicine instructions when giving treatment. They received very little information from the pharmacist on how to give the medicine and they did not have a lot of experience in administering Amoxicillin. Furthermore, none of these three caregivers were informed in the past that you should give the complete treatment course; the pictorial medicine instructions taught them to adhere for all the disease to disappear. They learned this because of the way the bacteria are drawn, how they are reducing every day. This explained to them to give the medicine every day and to not skip a dose.

"I was not told when to give, how much and for how many days, but the pharmacist gave me a paper where those things were written. So I just read and understood. It told me to give for five days and that I had to pour. [...] It also told me that you should give for 5 days for all the disease to disappear. [...] Cause you can't stop on the third day because then there is still disease. (Caregiver H)"

6.2.5 Summary of reasons for what reason caregivers gave the Amoxicillin syrup the way they did

To sum up, caregivers were influenced by the pharmacists' instructions, past experiences, and incorrect understanding of the correct use of the Amoxicillin syrup treatment instructions when they administered the Amoxicillin syrup to their child.

The pharmacists never provided complete instructions to the caregivers. For all of them they wrote down 1x3 indicating that they should give it three times a day and to most caregivers they explained how to prepare the medicine. However, other aspects such as which dose to give and to give for five days were rarely mentioned and in none of the cases they instructed the caregivers to pour the medicine after finishing the treatment course. Pharmacists are aware that they give too little instructions and blame it on time pressure, the assumption the caregivers already know how to give Amoxicillin syrup or the caregivers' presumed inability to understand treatment instructions.

The majority of the caregivers recalled more instructions than they actually received from the pharmacists. Furthermore, many of them said they followed these

instructions when they used the Amoxicillin syrup. For all caregivers this led to a correct preparation of the Amoxicillin syrup. The caregivers who read the pictorial medicine instructions recalled receiving correct treatment instructions, which lead to correct actions. In contrast, many caregivers who did not use these instructions recalled receiving incorrect treatment instructions, which lead to incorrect actions. In addition, the caregivers who did not use the pictorial medicine instructions sometimes misinterpreted the treatment instructions they got from the pharmacists.

The majority of caregivers who read the pictorial medicine instructions and some of the caregivers who did not read them were told in the past that it is important to complete the treatment course for the disease to completely disappear. Some of them were advised in the past during a visit at the clinic or by being on ARV treatment and many caregivers who read the pictorials learned about the importance of finishing a full course after they had stopped giving treatment and when the disease had re-occurred. There was a difference between the groups in how they define “completing a treatment course”. According to the caregivers who read the pictorial instructions you finished the course after five days, while the caregivers who did not read the instructions thought it meant you have to give the syrup until it is finished or until the child is feeling better.

Furthermore, almost all caregivers used Amoxicillin syrup before. Many caregivers who did not read the pictorial instructions gave the same dose or for the same number of days as they did in the past and in most cases this was an inaccurate dose or an incorrect number of days. Few caregivers who read the pictorial instructions said they gave the same way was they did in the past but the ones who did all gave a correct dose for five days.

Caregivers who kept the remaining Amoxicillin syrup kept it because they thought it could be used again the next time a child falls sick. In addition, many caregivers who did not read the pictorial medicine instructions said they would have kept the syrup for this reason if some had remained. Some caregivers who did not read the pictorial instructions were afraid to overdose their child, which lead to giving a wrong dose, for the wrong number of days or in giving only two doses a day.

Lastly, caregivers who used the pictorial medicine instructions were influenced by the pictorials in three ways: 1) the instructions confirmed what the caregivers already knew, or 2) they confirmed some information the caregivers already knew and taught them some new information, or 3) caregivers did not know how to use Amoxicillin syrup yet and learned everything from the pictorial medicine instructions.

6.3 Caregivers' understanding, perceptions and recommendations for future use of the pictorial medicine instructions

This section describes how the caregivers used and perceived the pictorial medicine instructions after they received them from the pharmacists, the messages that they identified in the pictorial instructions during the interview, what they learned from these instructions, their perception of usefulness of the pictorial medicine instructions and recommendations for future use of such pictorial instructions.

6.3.1 How the caregivers used and perceived the pictorial medicine instructions after they received them from the pharmacists

Almost all caregivers who followed the pictorial medicine instructions immediately read them after they came home from the clinic. One caregiver looked at the pictorial instructions the following day because she had forgotten about it. They read the instructions because they were instructed to do so by the pharmacists, because they were curious what the paper was for or because they felt uncertain about aspects of the treatment course and were hoping to find information in the pictorial instructions leaflet.

“You know. She did not tell me about when to go give and for how many days, but she gave me a paper that those things were written. [...] So when I came with this paper at home, I opened it and read it a bit to find out those things. So this is where I learnt from this paper. I just read it and understood.” (Caregiver H)

After reading the pictorial medicine instructions all of them understood that it was advising them how to give Amoxicillin syrup to treat pneumonia.

“That paper was saying how to mix the drug, how to give every day and if you give this day the disease will be this much and the next day you see the disease reduces, next day again and then on the fifth day you see the child is good. And on the sixth day the drug is not working anymore, so you pour it out. (Caregiver Q)”

Nine caregivers who did not read the pictorial medicine instructions had forgotten they received them. They explained they were busy and that their mind was not on the pictorial instructions. Two others remembered receiving the instructions and they thought they would be useless.

“You know when a child is sick your mind is on the child and not on that paper [...] You don’t have any idea how that paper can help, you see it as nonsense sort of. I have given this medicine many times before, so I did not see how this paper could help me. I already knew how to give it. (Caregiver F)”

The other caregivers said they had a brief look at the pictorial medicine instructions, but did not read the leaflet. Two of them identified that the leaflet was telling them about how to administer the Amoxicillin syrup and the other two recognized the leaflet was showing them how to hold the baby.

“There was one picture showing me how I should hold the baby while I’m giving the medicine. [...] It was a picture of a mother holding her child while she is giving the child the medicine to drink. (Caregiver R)”

6.3.2 Identified messages in the pictorial medicine instructions

All caregivers were given the pictorial medicine instructions at some point during the interviews. While they hold the leaflet caregivers were asked to describe anything they could see in the pictorial medicine instructions using the same interview techniques as during the pretesting interviews.

Preparation

All caregivers identified that you should add water in the bottle and shake before using the medicine

Treatment course

All caregivers identified that you should administer the medicine three times a day in the morning, midday and evening. They identified the time by the pictograms of the sun and moon. Furthermore, all caregivers said that the pictorial medicine instructions show them that you should give the dose according to the age of the child, and you use the bottle top of the Amoxicillin syrup bottle.

All the caregivers explained that the pictorials told them to give the medicine for five days.

Pour out remaining medicine

All except one caregiver said that the drawing on the sixth day shows that you should pour out the remaining medicine. The caregiver who read the pictorial medicine instructions but who stopped giving after the first day because her child vomited after each dose thought that the drawing of pouring out the medicine meant that on the sixth day you should add water with the remaining medicine and then give the entire bottle to the child.

Not all caregivers could read Kiswahili. Six caregivers could not read the reason why the medicine should be poured. Five of them thought it would be better to keep the medicine in case the disease re-occurs or another child gets sick. Three of them did not use the pictorial medicine instructions and two of them used the instructions.

“For me, I like to keep the medicine in case my child gets sick again. So I think that there should be a different version of this paper for mothers who would like to keep the medicine instead of pouring.” (Caregiver U)

“Pneumonia dots” as explanation of why to finish complete treatment course

All but one caregiver said that the dots show how much pneumonia or disease there is in the body and every day you administer the medicine the disease reduces.

”You see in the picture here how they’ve drawn it, they’ve drawn that in the first day the child has got a lot of viruses, isn’t it? But the fifth day the virus is now almost gone, it has reduced, that means that the drugs is working in his body very well if you give it every day. And on the sixth day you see the virus is not there now. (Caregiver Z)”

One caregiver who did not use the instructions thought that according to the dots you should give a smaller dose once the disease starts reducing. After the interview we explained to her that dots were intended to show that pneumonia is reducing every day, but that you have to give the same dose according to the age of the child for five days. However, during the focus group discussion about a month after the interview, she still thought that the dots were telling you that you have to reduce the dose when the disease starts reducing.

"The dots show that the first day there is a lot of pneumonia, the second day pneumonia is just a bit, the third day pneumonia is reduced, the fourth day its little same for the fifth day and on the sixth day there is no pneumonia.[..] They also show that you should give more medicine the first three days because there is more disease, and you can give less medicine the other days. [..] For example my child falls here (1 month to 1 year), so the day 1 I give her 2.5ml, day 2 the same, day 3 the same, and on the fourth and fifth day I give her less than 2.5ml. (Caregiver R)"

The adherence story on the back page

All caregivers said that the back page of the pictorial instruction leaflet explains how the child recovers and pneumonia reduces every day as you give the medicine. One caregiver explains:

"You know these pictures, it is the same as with my child. You know when I took her to the hospital she was seriously sick, she looked liked the child here on the first day. And then I started giving the medicine and on the second day she could open her eyes, on the third day she woke up and could play a bit, the fourth day she could stand just like the child here and on the fifth one, she was just normal, just as this picture here. [..] So this shows how the child gets better when you give the child the syrup continuously. (Caregiver O)"

Two caregivers who did not use the pictorial medicine instructions thought at first that the child was five different children of a different age and that each pictogram tells them how to hold the child of that age when giving the medicine. However, when we told them the pictorials intended to show the same child every day, they changed their mind and said they saw a child recovering every day because s/he was taking the medicine.

The majority of the caregivers saw the pneumonia bacteria or disease as the reason to administer the Amoxicillin continuously for five days, because if you would stop on the third day there will still be disease in the body. However, three caregivers who did not use the pictorial medicine instructions recognized the dots as representing pneumonia, the disease or the cough and saw that it was reducing every day. But when they were asked what they would do if their child is feeling better on the third day, they answered that they would stop giving the medicine.

“If the child is doing well at that third day she can just stop, because the child is better now. (Caregiver I)”

6.3.3 Learning from the pictorial medicine instructions

This section first describes what the caregivers who used the pictorial medicine instructions learned from the pictorial instructions. Secondly it describes what the caregivers who did not use the pictorial medicine instructions learned from the instructions after they read them during the interview.

6.3.3.1 What caregivers who used the pictorial medicine instructions learned from these instructions

Three caregivers learned from the pictorial medicine instructions that it is important to finish the full course for all the disease to disappear.

“I’ve learned from the paper that the disease reduces. Because if I look at the red dots, I’m able to see the concentration of the drug. Because it tells that if you give on the first day there is a lot, on the second day not that much, third day, fourth day reducing like that, and then you see here on the sixth day its gone that is when you pour. [...] So it has taught me that I should keep on giving and not skip a dose. (Caregiver U)”

For the other caregivers the adherence story was a reinforced learning, they were already told in the past that it is important to give the full treatment course. However, they all said that the pictorial medicine instructions elaborates more on it because of the way the pneumonia is drawn. You see the dots reducing every day so if you stop before the fifth day there is still some disease and that is why you have to give for five days.

Six caregivers said they did not know for how many days to give the medicine and that pictorial medicine instructions has taught them to give the medicine for five days. In the past they often gave until all the medicine got finished or until the child got better. One of them explained during the focus group discussion:

“Okay for me, I am lazy, when giving the medicine for two three days, I was lazy and when I see she has a change. I felt the child was ok. So when I looked at this picture, I found out that you should not be lazy, when you are lazy and you are not giving the medicine that is when the disease can come back, it will come back very serious.”
(Caregiver G)

Seven caregivers learned from the pictorial instructions that you should pour the remaining medicine because it expires after you mixed it with water. In the past they used to keep it. Furthermore, five caregivers explained that they learned that you should give the dose according to the age of the child.

“This paper taught me a lot because those people told me just give three times a day. So without I could just have given 10 times or until its finished.[..] So you just give the child to finish the drug and you don’t know when to stop giving, and you don’t know you might be hurting your child. [..] And sometimes you might think this child I just give the full bottle top because he is very sick, but it should not be given like that. I learnt that from 1 year to 3 years it should be given 5 ml. (Caregiver M)”

6.3.3.2 What caregivers who did not use the pictorial medicine instructions learned from these instructions

All caregivers who did not use the pictorial medicine instructions when giving the Amoxicillin to their own child, did use these instructions during the interviews when they were asked how they would advise a neighbour on the use of Amoxicillin syrup. Furthermore, when using the pictorial medicine instructions all except one caregiver gave correct advice to the “neighbour” about the Amoxicillin treatment course. The difference between how they administered Amoxicillin without the pictorial medicine instructions and how they advised about how to use Amoxicillin with these instructions is shown in Table 3.

Table 3. Caregivers' correct and incorrect advice to neighbour about giving the treatment course

		Dose	3 times a day	5 days	Treatment regime	Treatment course	Pour out remaining
How the caregivers gave treatment to their own child without reading pictorials	Incorrect actions	10	1	11	11	14	2
	Correct actions	4	12	3	3	0	12
How the caregivers advised another mother to give treatment when reading pictorials	Incorrect actions	1	0	0	0	1	0
	Correct actions	13	14	14	14	13	14

Caregivers learned about the correct dose for age and for how many days to give the medicine. Many caregivers said the pictorial medicine instructions taught them that Amoxicillin should be administered for five days and that it is important to not skip a dose during those five days.

"Hmm because mostly we mothers at times we make mistakes. Sometimes you've given the child medicine for two three days and then you see the child is feeling better then now you forget about that medicine, you don't give the child anymore. But what I've learnt from looking at the pictogram is that we are supposed to give the medicine according to how it should be given until the last day that it should be given. [...] Because if you stop on the way then those remaining days the disease is going to accumulate and come back as in the first day. (Caregiver L)"

Furthermore, caregivers who had learned in the past that it is important to complete the full treatment course, explained that the pictorial medicine instructions has taught them what finishing the course means.

"Now I realize that finishing the dose is not finishing the complete medicine, but it is to finish the number of days you should give the medicine. If you give for those 5 days that is when you have finished the dose and when the disease has cured. (Caregiver B)"

6.3.4 Perceptions of usefulness of the pictorial medicine instructions

All the caregivers found the pictorial medicine instructions useful to see what Amoxicillin treatment course you have to give to your child. Even the caregivers who did not use the instructions when giving Amoxicillin to their own child found the

pictorial medicine instructions helpful after they had read the instructions during the interview.

A main reason for twelve caregivers for finding the pictorial medicine instructions useful was because it gives more information than the pharmacists and it elaborates more on why you have to give the Amoxicillin syrup. Furthermore, ten caregivers said they found the pictorial medicine instructions useful because it encourages to give the medicine continuously for five days, you can see how the bacteria are reducing every day and because it is drawn how the child gets better every day it gets the medicine.

“I looked at the paper and saw here at day one the child is very sick, and when you look here (at day five) you see the child is okay and she can play. It’s true because on the fifth day you see your child can run. I loved that because if you look at the first day the child is coughing, even if you give her the medicine she is still coughing, and then when I continue giving my child got better the same as this baby. So when I looked at the paper, I saw these people have done it well because you see here the child is not okay, and here you see the child is playing. So that’s why they were saying that you have to finish the dose [...] so it encouraged me to give the child the medicine every day because I knew she was going to be cured.” (Caregiver M)

Furthermore, seven caregivers said they found the instructions helpful because they were something practical, as you see exactly what you have to do and you can see how the child gets better.

“It opens our minds as mothers. It tells us more about how to use the drug. It is describing the use of drug and actually if somebody is attentive, it can give full information about to use it. It has taught me a lot that which I used to not know, and it tells me more than the pharmacists did. [...] They are good because you see step by step what you need to do.” (Caregiver P)

One caregiver who did not use the pictorial instructions and two caregivers who used the instructions found the pictorial medicine instructions useful because now that they have them they don not have to go to the clinic anymore when the child is coughing.

They can just go to the pharmacy and buy Amoxicillin syrup and see on the pictorial medicine instructions how they should give it.

One caregiver shared a story how the instructions have been useful when a neighbour came to her to ask for advice, during the focus group discussion with caregivers who had used the pictorial medicine instruction.

“This paper helped another lady when she came to me because her child was also sick, she went to the hospital and she was given Amoxyl but she was not given this paper, so she gave the child the medicine twice and she came to me that Mama Rony I don’t see any change I am going the child the medicine and the child is still coughing. And I told her that let me show you a paper I have here, so you see how those things are reducing slowly. So it is not something that you give the child ones or twice and then you stop because those bacteria are still there, they are not yet finished. So it helped that lady.” (Caregiver S)

6.3.5 Recommendations for future use of the pictorial medicine instructions

The caregivers who used the pictorial medicine instructions and the caregivers who did not use these instructions differed in their recommendations for future use of the pictorial medicine instructions. During the focus group discussion with the caregivers who did not use the instructions the caregivers said that instructions like these should be used in the future, however pictorial medicine instructions cannot work on their own: The pharmacist has to explain what the medicine instructions are for, and she cannot just assume that the caregivers will understand the instructions. Therefore, she has to explain how to use the medicine and how to use the pictorial instructions, and then the pictorial medicine instructions is a tool that elaborates more on the oral instructions.

“You see, these instructions (pictorials) they tell us a lot and they encourage you so they should use them. [...] But those sisters should teach us, how to give the child the medicine before they give us the medicine [...]. They should tells us the days you should give and for how many times [...]. Because if they don’t tell us the way we should use the medicine, there is no reason for them to just give you to paper.

Because if you don't know how to give, and you don't know how to read or you don't understand how to use the paper then how do the mothers know what to do? [...] So they (pharmacist) should still explain, and then give you the paper so you can go home and she what she has explained.” (Caregiver O)

That the caregivers prefer the pictorial instructions to be accompanied by oral instructions also came up during the individual interviews. Six caregivers who did not use the pictorial medicine instructions were not told anything about them when they received it. They all thought that the pharmacist should have explained better what the pictorials were for, for them to have a look at the instructions.

”She gave me this paper and when she gave it to me she didn't tell me anything, she didn't tell me to go and look at the paper first and that's when you give the child the medicine. Meaning that I didn't look at the paper for me to be able to give the medicine in the right way. She should have told me better. (Caregiver O)”

The caregivers who used the pictorial medicine instructions have a different opinion. During the focus group discussion they discussed that pictorial medicine instructions like these should be used in the future because the pharmacists often does not explain anything. Therefore, having an instruction leaflet that you can understand, even if you cannot read, will help caregivers to give the medicine.

“Because sometimes those sisters they sometimes come from the house with a bad mood, and then she is not going to explain to you how to give or write all these things down for you. [...] So for them to encourage us is for them to fold the paper and insert inside the box, because even if you don't know you can read the paper [...] you go and look what you have to do, even if you don't know how to read, you look at it and you know what's in there and you understand.” (Caregiver J)

6.3.6 Caregivers preference for including an adherence story in pictorial medicine instructions

During the focus group discussions the caregivers were shown the PATH prototype and in both group discussion all the messages in the PATH pictorials were identified.

Even though all caregivers in both groups understood the PATH pictorials equally well as the pictorial medicine instructions for the Amoxicillin syrup, they all preferred the latter.

A reason the caregivers gave was because the drawings of the mothers and children resemble them. Furthermore, the adherence story came up as the main reason for the caregivers to prefer the pictorial instructions. In both groups the caregivers discussed that the pictorial of the Amoxicillin syrup encourages you to follow the instructions because of the drawings on the back page. The PATH prototype did not have an adherence story, and therefore they thought the pictorial medicine instructions for the Amoxicillin syrup would be a better instruction leaflet.

Finally, all the caregivers who used the pictorial medicine instructions started with explaining the adherence story on the back page when they received the instructions during the interview. This could indicate that this is what the caregivers remembered and liked best from the pictorial medicine instructions, which supports the findings from the focus group discussion that the adherence story was a main reason for preferring the instructions for the Amoxicillin syrup.

6.3.7 Summary of caregivers' understanding, perceptions and recommendations for future use of the pictorial medicine instructions

To summarize, almost all caregivers who used the pictorial medicine instructions immediately read these instructions and understood that they were treatment instructions for Amoxicillin syrup to treat childhood pneumonia. Most caregivers who did not use the instructions forgot about them or did not think the instructions could be helpful. Some of them had a brief look and recognized that it showed how to hold the baby when giving the syrup or that it was about the Amoxicillin syrup.

During the interview all caregivers identified the messages about how to prepare and give the Amoxicillin syrup. However, there were some caregivers who could not read Kiswahili and could not identify a reason of why to pour out the remaining medicine. These caregivers said it they would keep the remaining medicine so that they could use it again the next time the child is sick.

Almost all the caregivers identified the adherence story as the reason why you have to give the medicine according to the instruction, only then the child will heal. In addition, most of them said that you cannot skip a dose otherwise there is still disease in the body. Furthermore, during the focus group discussions there was a clear preference for including an adherence story in the pictorial medicine instructions. However two caregivers who did not use the instructions had some difficulties identifying these messages at first. Some other caregivers who did not use the instructions identified the messages, but still believed it would be better to stop giving the Amoxicillin syrup when the child is feeling better.

Some caregivers who used the pictorial medicine instructions said the instructions taught them what dose to give, that they have to give for five days, and that they have to follow the treatment instructions to recover from all the disease. Other caregivers who used the instructions said that the instructions elaborated more on previous knowledge.

Caregivers who did not use the pictorial medicine instructions gave an incorrect Amoxicillin treatment course to their child. However, during the interview they advised a “neighbour” to take the treatment correctly. The majority said that they learned from the instructions that you have to follow the instructions for all the disease to disappear and the child recover. Some of them explained that the pictorial instructions taught them that finishing a course means that you have to give the Amoxicillin syrup for five days.

All caregiver found the pictorial medicine instructions useful. Reasons they listed were because they included more information and explanation than the oral instructions you get from the pharmacists, because they are practical and you can see what you have to do and because the pictorials, especially the adherence story, encourages to administer the Amoxicillin syrup according to the instruction leaflet.

However, there was a difference between the caregivers who used the pictorial medicine instruction and the caregivers who did not use them in their recommendation for future use. Caregivers who used the instructions said they should come as an insert with the syrup so you could read it. Pharmacists often give

incomplete or no instructions and therefore the pictorial instructions could help you to give the Amoxicillin syrup correctly. Caregivers who did not use the instructions said that the pictorial medicine instructions would not work on their own. They said the pharmacists have to explain the Amoxicillin instructions and how to use the pictorial instructions in order for a caregiver to administer the Amoxicillin syrup correctly.

7. Discussion of research findings

The aim of this study was to answer three research questions:

- How do caregivers give an antibiotic treatment?
- For what reason do caregivers give an antibiotic treatment the way they do?
- Does including pictorial medicine instructions with an antibiotic medicine have an influence on how treatment is given? If so, in what way?

This section answers these questions by discussing the research findings reported in the previous chapter. Additionally it gives recommendations for future research and for the use of pictorial medicine instructions.

7.1 How caregivers gave the Amoxicillin syrup – the influence of the pictorial medicine instructions

This section first describes how caregivers administered the Amoxicillin syrup and the influence of the pictorial medicine instructions on this; secondly it describes the influence of the pictorial instructions on adherence. Furthermore, it describes how caregivers who used the pictorial instructions were influenced by these instructions. Finally it gives a possible explanation why some caregivers used and some of them did not use the pictorial instructions when administering the Amoxicillin syrup.

7.1.1 The influence of the pictorial medicine instructions on how treatment is given

The findings show a clear difference in how Amoxicillin syrup for childhood pneumonia is given between caregivers who used the pictorial medicine instructions and caregivers who did not use them. All but two caregivers who used the pictorial medicine instructions gave the Amoxicillin syrup according to these instructions. In contrast, none of the caregivers who did not use the pictorial instructions gave a

correct treatment course. They either gave a wrong treatment regime, gave the medicine for an incorrect number of days, or both.

These findings are in line with the alarming reports regarding the use of antibiotic medicines (Holloway & Dijk van, 2011; World Economic Forum, 2013). WHO estimated non-adherence to antibiotic instructions to be around 50% globally (Holloway & Dijk van, 2011). In this study, half of the caregivers administered the Amoxicillin syrup incorrectly. Almost all of them did not use the pictorial medicine instructions. Even though the findings of this study cannot be generalised, they indicate that pictorial medicine instructions can help a patient or caregiver to adhere to the treatment instructions when taking the medicine.

7.1.2 The influence of the pictorial medicine instructions on adherence

The findings indicate that providing caregivers with an adherence story that explain why they have to give the full treatment course can motivate them to give the Amoxicillin syrup according to the instructions. The majority of the caregivers who used the pictorial medicine instructions said that because of the adherence story in the pictorials they felt encouraged or motivated to give the Amoxicillin syrup according to the instructions. They understood the pictograms with the pneumonia bacteria reducing and the child recovering and linked this to their own child when administering the Amoxicillin syrup. Some caregivers already knew the importance of adherence because they learned or experienced this in the past, however they said that the adherence story elaborated more on their previous knowledge.

Secondly, all the caregivers used the pictorial instructions and gave correct treatment instructions to a “neighbour” on how to use the Amoxicillin syrup, even though they did not use these instructions when giving the medicine to their own child. They said the caregivers cannot stop giving treatment when the child is feeling better before the fifth day, because it is shown in the adherence story that even though the child is feeling better, there is still disease in the body.

Furthermore, during the pretesting interviews as well as during all the focus group discussions the adherence story was said to be a main reason for caregivers to prefer the pictorial medicine instructions over the PATH prototype. Thus, an explanation of why to adhere is not only understood by the caregivers, but also preferred by the majority of them. This is supported by the studies on the Lapdap (chlorproguanil-dapsone) and Coartem (artemether – lumefantrine) pictorial instructions were the majority of respondents preferred a version of the of the pictorial instructions that included the parasite boxes over a version of the instructions that did not include these boxes as an explanation of why to adhere (Haaland 1a & 1b, unpublished)

7.1.3 How caregivers used the pictorial medicine instructions

The caregivers who used the pictorial medicine instructions when administering the Amoxicillin syrup to their child mentioned three different ways of using them: for some the information were completely new learning, for some it confirmed everything they already knew about giving Amoxicillin syrup and for the majority it confirmed some things they already knew and it also taught them new things.

This influence of the pictorial medicine instructions can be explained by Albert Bandura's (1977) Social Learning model, the theoretical framework also used by Ngoh & Shepherd (1997) to explain learning through visual aids:

Attention and Comprehension

In Albert Bandura's model the first step of learning is attention to the modelled behaviour, in this study the behaviour shown in the pictorial medicine instructions. The caregivers who used the instructions, first paid attention to these instructions, recognized the objects and identified the messages in the instructions.

However, in order to administer the Amoxicillin according to these instructions it is not only important to pay attention to the pictorial medicine instructions but also to understand the messages they carry. If the caregivers do not understand the messages in the pictorial instruction, they cannot learn from them and administer the Amoxicillin syrup correctly. Therefore, to apply the Social learning model on the pictorial instructions comprehension should be added in this first step of learning.

Almost all the caregivers who used the pictorial instructions interpreted the objects in the pictograms and the meaning of the messages correctly. Two caregivers recognized that the pictogram of the remaining medicine being poured, but did not understand the reason why they had to pour it because they could not read Kiswahili. Therefore, they decided to keep the remaining medicine. One of them did also not identify the correct dose to give to her child and administered a too high dose for the age of her baby.

Retention

After all the objects were recognized and messages were interpreted, the caregiver stored them cognitively as mental representations. When information is represented cognitively, this is coded with other relevant information (Bandura, 1977). This can explain the different ways in which the caregivers used the pictorial medicine instructions. For caregivers who already knew all the information in the pictorials, their already existing mental representations of how to give Amoxicillin syrup were reinforced. For the caregivers who learned something new from the pictorial instructions, this new information was coded together with already existing mental representations about how to give Amoxicillin syrup or other medicines that was reinforced by the pictorial instructions.

Furthermore, the retention phase could also explain the reason why caregivers who used the pictorials all recalled receiving correct oral instructions from the pharmacists (although they had in fact not received complete instructions), and shared perceptions and past experiences that supported the information in the pictorial medicine instructions. The information that they read in the pictorial medicine instructions complemented and reinforced the correct treatment actions that they had heard or performed in the past and overruled incorrect knowledge or actions. Therefore, when sharing these memories about past experiences or the pharmacists' instructions during the interviews they remembered it according to the correct Amoxicillin instructions.

Motor reproduction processes

After the information of the pictorial medicine instructions is represented cognitively, these messages are translated into possible actions (Bandura, 1977). This means that the caregivers assess whether it is possible to perform the behaviour guided by the

instructions, and in what way they have to perform it. In other words, the caregivers assess how they are going to give the treatment. Since all the caregivers gave the medicine according to the pictorial medicine instructions, they must have perceived themselves as being capable to follow the instructions.

Motivation processes

To actually perform the guided behaviour, and give the medicine according to the pictorial medicine instructions, the caregivers have to feel motivated to do so (Bandura, 1977). The majority of the caregivers felt encouraged by the pictorial medicine instructions to give the Amoxicillin syrup according to these instructions. Furthermore, some of the caregivers administered a medicine incorrectly in the past and remembered the bad consequences, which could have motivated them to follow the treatment instructions.

7.1.4 Explanation why some caregivers used and some caregivers did not use the pictorial medicine instructions

The caregivers who used the pictorial medicine instructions seemed to differ from the caregivers who did not use the instructions in their motivation to be adherent because of their awareness of the possibility to give a treatment incorrectly and of their confidence in their ability to read and understand the pictorial medicine instructions. This supports the HSM model, in which motivation and ability are determining factors whether someone is using more in-depth systematic information processing or more heuristic, short-cue information processing to determine an action (Chaicken & Trope, 1999; Maio & Haddock, 2010). According to the model, the caregivers who used the pictorial instructions used systematic processing, and thought about the medicine instructions more carefully than the caregivers who did not read the pictorial instructions who used short cues such as their perceptions, past experience and the pharmacists' instructions about the treatment to determine their action.

Some of the caregivers who used the pictorial medicine instructions stopped giving treatment in the past before the treatment course was finished, and as a result they or their child got really sick again. Other caregivers were told in the past that it is important to give the full treatment course. Knowing the consequences of giving an incorrect treatment course or the importance of giving a complete course most likely

influence the motivation to follow treatment instructions when giving a medicine. This is supported by the *health risk theory* (Das, de Wit & Stroebe, 2003), which argues that people assess their health risk when attending and adhering to health messages. This means that they assess how vulnerable they are and how severe the risk is. In case the vulnerability and risk is perceived as high people are more likely to use systematic processing, and attend and adhere to the health messages. Therefore, caregivers who experienced how a disease can re-occur when treatment is not giving correctly most likely perceived themselves being at risk and thus read the pictorial medicine instructions.

Furthermore, it seemed that many of the caregivers who used the pictorial instructions were aware that they could administer the medicine incorrectly. According to the HSM heuristics will be used as long as they give a person confidence to perform a behaviour, also known as the *Sufficiency threshold* (Chaicken & Trope, 1999; Maio & Haddock, 2010). Being aware that you can give a treatment incorrectly could influence the caregivers' confidence in administering the treatment. Their insecurity to base treatment on the oral instructions or on past experience or perceptions about the Amoxicillin syrup could have made them decide to read the pictorial instructions instead.

The sufficiency threshold could also explain why half of the caregivers did not read the pictorial medicine instructions. None of them had realized they gave the Amoxicillin syrup incorrectly until they looked at the pictorial medicine instructions during the individual interviews. Thus they were confident in their ability to give the treatment based on the oral instructions from the pharmacist and their past experiences and perceptions about Amoxicillin syrup. This could have decreased their motivation to use the pictorial medicine instructions. Furthermore, the guiding belief of the HSM that the mind processes with the least amount of effort, could explain why half of the caregivers did not read the pictorial medicine instructions.

Finally, there was a clear difference between the caregivers of the two focus group discussion in their opinions about how pictorial medicine instructions should be used. The caregivers who used the instructions said that such instructions should come as an insert with the Amoxicillin syrup. The caregivers who did not use the pictorial

medicine instructions did not believe these instructions would be effective without any oral communication. They said that the pharmacists should communicate how to use the medicine and that you cannot assume that the caregiver will understand the pictorial medicine instructions on her/his own. This indicates that perhaps some of the caregivers who did not use the pictorial medicine instructions did not perceive themselves to be able to read and understand the instructions when they received them from the pharmacist. This is supported by the *enhancement hypothesis* of the Heuristic Systematic model (Maio & Haddock, 2010), which argues that people will use heuristic cues when they feel that they are unable to perform systematic processing, which in this case is reading the pictorial medicine instructions.

7.2 How caregivers gave treatment – the influence of communication, perceptions and understanding of disease and treatment instructions

Previous studies have found that the following factors influence adherence to short-term treatment: communication between health provider and the patient perceptions of disease and treatment and understanding of the treatment instructions (DiMatteo, 2004; Davey & Hayes, 2002; Krueger, Felkey, & Berger, 2003; Kucukarslan, 2012; Lim & Teh, 2012; Oh et al., 2011; Vermeire et al., 2001; Zolnierek & DiMatteo, 2009; Vermeire et al., 2001). This study confirmed these findings, as all caregivers, both those who used and who did not use the pictorial instructions, were influenced by these factors. Furthermore, the findings show that it is not just one of these factors that influenced how the caregivers gave the treatment but a combination of all these influencing factors.

7.2.1 Communication between the pharmacist and caregivers

The pharmacists gave incomplete instructions about the Amoxicillin syrup to the caregivers. Nonetheless, caregivers recalled receiving more instructions than they were told and the majority said that they “just gave treatment” as they were told by the pharmacist. There are two possible explanations for what reason caregivers recalled more instructions than they were actually given by the pharmacists and for what reason they said to be influenced by these, recalled, instructions.

Firstly, in Kenya there is a strong hierarchal order based on someone’s socio-economic status and profession. In other words, as a patient you are expected to do as

the pharmacist or other health providers instructed you to do. Thus it is possible that during the interviews caregivers said they gave the medicine as instructed by the pharmacist, as a social desirable answer. The way they gave the treatment is what they said the pharmacist instructed them to do.

Even though following the pharmacist's instructions could be a socially desirable answer, there were a few caregivers who recalled the pharmacist giving them incomplete instructions. Furthermore, during the focus group discussions the caregivers were critical towards the oral instructions they received from the pharmacists. They said pharmacists give too few instructions and that you often go home not exactly knowing what you have to do. Therefore, it might also be that caregivers actually recalled the oral instructions differently than told, also known as *recall bias* (Raphael, 1987). The memory of the oral instructions of the pharmacists are then mixed with other learning, memories or beliefs regarding treatment instructions for Amoxicillin syrup. In case of such recall bias, the caregivers are unaware that they recalled oral instructions differently than what they were told. Recall bias can be influenced by time duration and by the social desirability of the event (Raphael, 1987). Although the time between getting the oral instructions and recalling them is relatively short, following the instructions from the pharmacist is social desirable and thus could have influenced the memory of the oral instructions.

Whether the caregivers actually followed the pharmacist instructions as they recalled them or not, the findings support previous studies that found that patients are less likely to give correct treatment when the health provider is a poor communicator (Zolnierek & DiMatteo, 2009). In a global report on factors affecting antibiotic use from 1984 (Kunin et al.) it was pointed out that for patients, or caregivers, to understand and be able to follow a treatment regime the pharmacist has to:

- Explain the purpose and importance of the treatment
- Provide specific, detailed information about the treatment including dosage and duration
- Avoid medical jargon
- Support their explanation with written information
- Link the treatment schedule to daily activities
- Inquire and evaluate whether the patients understands the instructions

- Monitor the patients drug use over time

The findings of the observations show that the pharmacists barely gave instructions and, besides writing 1x3 on the medicine package, did not perform any of the recommendations listed 30 years ago to help caregivers to understand the treatment regime.

According to the concept of adherence the patient is the decision maker in how to take the medicine, based on agreement with the health provider. However it is questionable whether non-adherence can be blamed on the patient or caregiver when the pharmacist, or health provider, do not provide full instructions. This problem has also been identified by Ngoh and Shepherd (1997): “While understanding the drug regimen does not guarantee full adherence to drug therapy, lack of knowledge or understanding can prevent the most willing individual from complying”. In this setting none of the caregivers would have been able to make a correct decision, and thus to adhere to treatment instructions, if they would have followed the pharmacist instructions only.

7.2.2 Past experience with giving Amoxicillin syrup and perceptions and understanding of the disease and treatment

The caregivers who did not use the pictorial instructions were reliant on the incomplete pharmacists instructions, their past experience and their perceptions and understanding of the treatment instructions. The majority of them were not aware that how they administered the Amoxicillin syrup in the past was incorrect, such as giving a too high dose or for the wrong number of days, and used the medicine as they have been using it before.

Furthermore, many of them had learned in the past that it is important to finish the full course, however, they did not understand what it exactly means and used their own perceptions to interpret it. They shared misunderstandings regarding the definition of finishing a full course. Some caregivers thought that finishing a full course meant that you give until all the medicine got finished, or until the child is feeling better. The latter action could be dangerous for the child, since the pneumonia could re-occur even more heavily by stopping the treatment prematurely.

Other misunderstandings that were shared by many caregivers who did not use the pictorial medicine instructions were a scare to overdose their child, and the possibility to re-use the remaining medicine the next time a child falls sick. Saving the syrup is understandable economically, since Amoxicillin syrup can get out of stock at the public clinics and the caregivers then have to buy it at another pharmacy. However, this could be dangerous since the syrup loses its effect after it has been mixed with water and will therefore not be able to cure pneumonia.

Caregivers who used the pictorial medicine instructions were also influenced by past experiences and perceptions and understanding of the treatment instructions.

However, they were influenced by correct past experiences with administering the Amoxicillin syrup and the majority had perceptions and understanding of the disease and treatment that supported the pictorial medicine instructions. This indicates that the pictorial instructions reinforced their correct actions and understanding from the past, and corrected their incorrect actions and understanding by providing the correct treatment instructions and the reason why to adhere.

7.3 Recommendations for future studies

Based on the findings of this study there are several recommendations where future studies can focus. Firstly, this study uses a qualitative design and has a small study sample. A study with a big sample using quantitative methods such as the studies by Dowse and Ehlers (2005) and Ngoh and Shepherd (1997) could assess whether including pictorial medicine instructions to antibiotic medicines increases understanding and adherence compared to not receiving pictorial medicine instructions in settings where communication between health provider and patients are poor. This would strengthen the findings of this study that pictorial medicine instructions could help caregivers to follow treatment instructions. In addition, it can show that including pictorial medicine instructions is a relatively low-cost and effective intervention to increase adherence.

Furthermore, all the caregivers who participated in the pretesting interviews and focus group discussion as well as in the main study had relatively high education and health

literacy. The majority could also rely on the written text in the pictorial medicine instructions when giving treatment. In addition, for people who can read it is often easier to understand pictograms than for caregivers who cannot read. Future studies could focus on the influence of pictorial medicine instructions for caregivers or patients with no or low education, or low health literacy, to assess if and in what way they would use pictorial medicine instructions when giving treatment.

Thirdly, this study used a pictorial medicine instruction leaflet. Leaflets can be easily overlooked and not read, in this study only half of the caregivers had used the pictorial instructions. The aim of PATH and UNICEF is to develop a user-friendly pack of Amoxicillin dispersible, such as the Coartem dispersible (artemether – lumefantrine), where the instructions are printed directly on the blister pack. Therefore, the caregivers will see the instructions every time they administer the medicine. Future studies should investigate if printing the instructions directly on the medicine pack could increase the use of the pictorial instructions compared to the Amoxicillin syrup instructions leaflet.

The findings show that caregivers have a preference for shaded line drawings compared to abstract symbols for the pictorial medicine instructions. Furthermore, the pictorials for the Amoxicillin syrup instructions were better understood than the pictorials for the PATH prototype. PATH was not planning to pre-test their pictorial medicine instructions with the potential users. A future study could focus whether the use of abstract symbols that are less preferred and less understood than shaded line drawings have an influence on how caregivers or patients use the pictorial instructions and whether there is a difference in their influence on adherence. This could be relevant to advise organisations such as PATH and UNICEF who develop pictorial medicine instruction interventions, in what sort of pictograms to use and whom to pre-test with before the pictorial instructions would be used effectively by the potential users.

One of the objectives of this study was to explore how local perceptions of childhood pneumonia and treatment influenced the way caregivers gave the Amoxicillin syrup. The findings do not provide an answer to this objective, as this is a large question and requires a separate study. Future studies could focus on the influence of the

perception of the disease on how treatment is given and what role pictorial medicine instructions could have on this.

Finally, this study found that for the caregivers who used the pictorial medicine instructions, knowing the reason for why they have to follow the instructions was a motivational factor. The pictograms of pneumonia reducing were well understood in this study, and were based on parasite concept of the Lapdap (chlorproguanil-dapsone) and Coartem (artemether – lumefantrine) studies (Haaland 1a & 1b). By seeing pneumonia dots reducing and the child getting better every day the caregivers felt encouraged to continue giving treatment. Ngoh and Shepherd (2007) included an advanced organizer in their study to explain for what reason the patients had to administer the full treatment course. They did not find a significant difference in adherence between patients who received such an explanation with the pictorial instructions and patients who did not. However they explained this concept by using farming as a paradigm, and it could be that the patients did not link this paradigm to treating their own disease. A future study could assess this motivational factor in more depth by giving out both pictorial medicine instructions with the adherence message and pictorial medicine instructions without the adherence message. It could then be assessed whether the caregivers who are given a reason about why to finish the full course in the pictorial instructions differ in how and why they gave treatment compared to caregivers who do not receive this reason.

7.4 Recommendation for the use of pictorial medicine instructions for Amoxicillin syrup to treat childhood pneumonia in Kenya

The findings of this study show that including pictorial medicine instructions could be a low cost intervention to increase understanding and adherence to Amoxicillin syrup treatment instructions for childhood pneumonia in Kenya. Almost all the caregivers who used the pictorial medicine instructions gave the Amoxicillin syrup according to the instructions. Even though the sample size was small, it indicates that pictorial medicine instructions could help caregivers or patients to adhere to treatment instructions. Furthermore, researchers of previous studies on pictorial medicine instructions argued that for pictorials to be effective they have to be accompanied by communication about the instructions (Dowse & Ehlers, 2005; Ngoh & Shepherd,

1997, Yin et al., 2008). The findings of this study show that pictorial medicine instructions can be understood and used by caregivers when administering Amoxicillin syrup without additional communication about these instructions, provided that these instructions are carefully developed and pretested with the intended users before they are produced.

One could argue that only half of the caregivers used the instructions, and thus not all caregivers benefit from such intervention. However, it is likely that more caregivers will benefit from the pictorial instructions over a period of time. An example is the caregiver who shared her story about a mother who came to her not knowing how to give the medicine, and how she used the pictorial medicine instructions to explain to her about how to use the Amoxicillin syrup. Secondly, studies on persuasive messages such as advertisement show that the more frequent someone receives information brochures the more likely it is that they will pay attention to it (Maio & Haddock, 2010). In Kenya childhood pneumonia is one of the most common diseases and most of the caregivers during the interviews had experience with Amoxicillin syrup in the past. Therefore, it is likely that many caregivers will receive the Amoxicillin syrup with the pictorial medicine instructions more often than just once and with each time the likelihood that they will read the pictorial instructions increases.

Finally, the pharmacists' responses to the findings from the observations show that the way they give treatment instructions is not likely to change easily. The pharmacists either denied the findings by saying that they did give full instructions, or they defended themselves by blaming their lack of giving full instructions their perception that the patients would not understand the instructions or on time pressure and workload at the clinics. While the latter was an important issue at the clinics, their response indicates that the pharmacists may continue to give incomplete treatment instructions. Therefore, by providing pictorial medicine instructions with the Amoxicillin syrup the caregivers would have an opportunity to read information about the treatment course that they most likely will not receive at the health facilities, and get help to understand how and why to give the full treatment course of the medicine to the child.

7.5 Conclusion

Non-adherence to antibiotics is a global public health problem (Davey & Hayes, 2002; Holloway & Dijk van, 2011; Pechere, Hughes, Kardas, & Cornaglia, 2007; World Economic Forum, 2013). The findings of this study suggests that pictorial medicine instructions, that provide an explanation of why to follow the treatment instructions, could potentially be a viable option to help caregivers or patients understand and adhere to antibiotic treatment instructions.

This study shows that pharmacists do not provide complete instructions to caregivers about how to use Amoxicillin syrup for childhood pneumonia. Caregivers who only followed their instructions, mostly gave the medicine incorrectly. Most caregivers who read the pictorial medicine instructions of the Amoxicillin syrup gave the medicine correctly. Even though the findings of this study cannot be generalised, they indicate that pictorial medicine instructions can help a patient or caregiver to adhere to the treatment instructions when taking the medicine.

Knowing the consequences of giving an incorrect treatment course or the importance of giving correct treatment course most likely influences the motivation to follow correct treatment instructions when giving a medicine. The majority of caregivers said they felt encouraged to give the medicine continuously because of the adherence story in the pictorial medicine instructions. Many caregivers who used the pictorial instructions were already aware off the importance of being adherent, this could have motivated them to follow the pictorial medicine instructions in the first place.

Finally, pictorial instructions need to be carefully developed, using visual perception principles, and pretested with the intended users to ensure that they will be well understood and helpful when administering a medicine.

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Appendix 1 – Interview guide pretesting interviews Kisumu

Objectives:

- Are pictograms (H) perceived the same in Kisumu as in Kilifi
- How is Amox syrup pictogram (H) used to explain instructions
- How are the PATH pictograms (G) perceived
- How is the PATH pictogram used to explain instructions
- What do mothers see as main difference between the 2 versions
- Which version do mothers prefer and for what reason

Tools:

G = Amox syrup pictogram

H = PATH pictogram for Amox dispersibles (not yet available)

Make sure that half of the respondents start with tool H and half with tool G to control for bias.

Interview guide

1. hand out leaflet, let mother hold them.
2. purpose interview: developing instructions for Amoxicillin syrup to make it easier for mothers like you to understand the instructions. That's why your input and advice is important
3. consent (sign & verbal for photos)
4. Perception of pictograms and use of instructions

Tool G, Amox syrup

Front

- What is happening? How do you think mom/child feels?
- What does this picture tell you? Or – how would you prepare the amoxicillin? What is it in the picture that tells you this?

Inside

- What is happening here?
- How old is it this child? How much medicine do you give to this child?
- How many times a day do you give medicine? When? What is it in the instruction that tells you this?
- For how many days?
- What do you do at day 6? (Why do you do this?)
- What do you think the red dots are?
- **How would you use these instructions to give medicine to your child?**

Back

- What is happening here? How is mother feeling? How is child feeling?
 - What are the dots?
 - How do you think story of child getting better and pneumonia reducing are connected?
 - Why is the child getting better and pneumonia reducing?
 - What would you do with the medicine if child is already better at day 3?
5. Give other tool. Introduce tool. Pictograms are also being developed for amox dispersibles, medicine like Coartem but then for pneumonia not yet on market (G)
 6. Perception of pictograms

Tool H, Amox dispersible

Preparation

What is happening here? OR How would you prepare the dispersibles? What is it in

the pictures that tells you this?

Instruction table

- What is happening here? How old do you think this child is?
- How much medicine do you give to this child?
- How many days do you give this medicine? How many times a day? What is it in the picture?
- What is happening at day 6?
- What are the dots? Why are they reducing?
- **How would you use these instructions to give medicine to your child?**

6. What are the main differences with tool

Probe: pictogram differences?

7. Which one do you prefer?

Probe: For what reason? What is it in the instructions?

Note: if preference is based on how to administer drug but not on how the tool looks like try to get mother focus on what is on the tool, the pictures such as drawing of mother giving medicine to child, different sun to display morning, different way babies are drawn.

Appendix 2 -Pretesting checklist

Time: **Date:** **Location:**

Tools to test (Cross of which tool we started with)

- Pictogram instructions amoxicillin syrup (A)
- Pictogram instructions amoxicillin dispersible (B)

Checklist interview

Syrup

Front

- Child is sick, coughing, mother concerned
- To prepare you add water and then shake

Inside

- Mother gives drug to child
- 1st baby between 1mth – 1 yr. Give 2.5 ml
- 2nd baby between 1yr – 3yr. Give 5 ml
- 3rd baby between 3yr – 5yr. Give 10 ml
- sun and moon indicates to give 3x a day, morning, midday and evening
- give for 5 days
- pour at day 6
- dots are pneumonia/bacteria/disease
- disease is reducing as you give medicine
- Able to apply on own child

Back

- story of child sick at day 1, getting better, healed at day 5
- pour med on day 6 cause won't work next time
- disease reducing
- connect disease reducing with child getting better with giving medicine

PATH

- 1st pic mother is giving medicine to child
- 1st pic child is between 2mnths – 1yr. Give 1 tab each time.
- 2nd pic is baby is between 1yr – 5 yr. Give 2 tabs each time
- sun and moon indicated to give 2x a day morning and evening
- give for 5 days
- after treatment pic show happy babies
- dots are bacteria and are reducing as you give med
- recognize that to prepare: take out tap, put on spoon, add water, wait to dissolve, give

Preference

- Syrup instructions or dispersible instructions. Reason:
- Which specific pictograms prefer:
 - mother and child
 - child
 - sun to show morning
 - bacteria

Suggestions for improvement

Age:

Occupation:

Schooling:

Place:

Appendix 3 – FGD guide for pretesting in Kilifi

Objectives:

Main:

- How would the pictorial medicine instructions be used to explain the use of amoxyl syrup to a mother who has a child with pneumonia

Sub:

- What aspects of the tools are well understood
- What aspects of the tools do the mothers have problems with
- If mothers have problems with tool how to deal with that
- How do the mothers like having such tool

Guide:

1. Hand out leaflet

2. Intro.

Explain purpose of the discussion and why them:

To develop instructions for Amoxicillin syrup to cure childhood pneumonia.

We want the tool to be easy understood and user friendly for mothers just like you.

Been to communities talking to mothers already and got a lot of input. Want to have this discussion to see how they would use such instructions and how to make the instructions even more acceptable and understandable for other women.

3. Divide into 3 pairs.

Ask them to instruct other mothers on how to give Amox to her child using the tool.

Let them work/discuss in pairs

4. Ask if there is anyone who would like to demonstrate how she would give instructions using the tool.

→ when mothers explains don't interrupt

→ after mother is finished don't evaluate, but appreciated

5. Ask if other mothers would like to contribute, would they do the same? Anything to add? Would they do something different?

6. Ask mothers what aspects of the tool are easy to understand

7. Ask the others what they found difficult with tool.

→ If things come up as being difficult ask; what could we do about that? How could we deal with that? (If a concept is not understood by the whole group, explain first)

8. If the following difficulties did not come up during the discussion share these and ask how we could deal with it:

“from the interviews we have seen that some mothers”

- connected dots not as being pneumonia but saw blood or rain instead

- medicine measuring cup as dose to give to child was not always recognized.

9. On finishing dose

“Do you know about women who do not finish full treatment?”

Let discuss, then:

“Would you think tool like this would make adhere better? Why?”

10. On throwing away med

“Do you know of mothers in community who save and re-use the medicine?”

let discuss, then:

“How do you think this tool will make mom pour med?”

11. How do you like this tool? Do you think this tool will help mothers given Amoxyl syrup to children? Why?

12. Any question you might have for us? Any info you would like to share that we have not talked about?

13. Thank and appreciated

Appendix 4 – FGD guide pretesting in Kisumu

Tools

G = amoxyl syrup instructions

H = Amoxyl dispersible instructions

Objectives:

- How tool G would be used to explain the use of amoxyl syrup to a mother who has a child with pneumonia
- How tool H would be used to explain the use of amoxyl dispersible to a mother who has a child with pneumonia
- What aspects of the tools are well understood
- What aspects of the tools do the mothers have problems with
- If mothers have problems with tool how it could be improved
- How do the mothers like having such tool
- Which tool do the mothers prefer and for what reason

Focus group discussion guide

1. *Intro and consent*

- Develop easy to understand instructions, their input important, have to be userfriendly for mothers just like you
- Written consent participating and tape-recording, verbal consent photos

2. *Role-play: "Explain to other mother how to give amox syrup with this tool"*

3. *"Who would like to demonstrate?"*

Probe: Anybody contribute? Anything to add? Would they do something different?
Ask Annemiek if she has questions

3. *"What aspects of the tool are easy to understand?"*

Ask Annemiek if she has questions

4. *"What aspects of the tool are difficult to understand?"*

Probe: What could we do about that?
Ask Annemiek if she has questions

5. *Role play: "Explain to other mother how to give amox dispersible with this tool"*

6. *"Who would like to demonstrate?"*

Probe: Anybody contribute? Anything to add? Would they do something different?
Ask Annemiek if she has questions

7. *"What aspects of the tool are easy to understand?"*

Ask Annemiek if she has questions

8. *"What aspects of the tool are difficult to understand?"*

Probe: What could we do about that?
Ask Annemiek if she has questions

9. *“How do you like having such tools?”*

Ask Annemiek if she has questions

10. *“Which tool do you prefer and why?”*

Probe: “Which pictograms show mother better, why? “Which pictogram show sun better, why? “Which pictogram show child better, why?” “Which pictogram show bacteria better, why?”

Ask Annemiek if she has questions

11. *“Do you know about women who do not finish treatment?”*

Probe: What could we do to make mothers adhere better? Would a tool like this work?

Ask Annemiek if she has questions

12. *“Do you know about women who do not pour left over syrup?”*

Probe: What could we do about it? Would this tool help?

Ask Annemiek if she has questions

13. *“Any questions you have for us?”*

14. *Thank and appreciated.*

Appendix 5 – Informed consent form pretesting FGD for participants in Kilifi and Kisumu

CONSENT TO PARTICIPATION IN RESEARCH

Study: The effect of pictogram labels on caregivers' understanding of how and why to give antibiotic treatment for childhood pneumonia as instructed.

Background and purpose

You are asked to participate in a study on the effect of pictogram labels on caregiver's understanding of how and why to give antibiotic treatment for childhood pneumonia as instructed. Pictograms have been developed for treatment instructions of the antibiotic to treat childhood pneumonia. Because you have a child yourself, I would like to invite you to this focus group to hear your perceptions on these pictograms.

My name is Annemiek and I am public health researcher and a social psychologist. At the moment I am doing research for my master degree in 'International Community Health' for the University of Oslo in Norway.

It is my hope that when I finish my research here, your information can be used to improve the pictograms. I am an independent researcher and doing this out of my own interest. I do not work for any organization and I am not paid by anyone to do this research.

What is a focus group discussion?

A focus group discussion is a group conversation where you will share your perceptions about the pictograms for treatment instructions of childhood pneumonia together with other caregivers of children from your community. The discussion may take up to two hours. I will use a tape recorder but you can refuse this and then I will take some notes instead. Since I do not speak your local language my assistant will be present to translate. I am interested in your perspectives, and I respect what you know. I will listen and learn from you.

Voluntary participation

To participate is entirely voluntary. You should not feel pressured to discuss issues that you do not want to talk about. You can end the discussion at anytime without telling me why you chose to do so. There will be no consequences of this. I would like you to know that your identity will be confidential. Your name and exact age will not be written anywhere and will never be used in relation to the information you share. Instead you will be presented by a code such as 'Caregiver a'. The recordings will be deleted once my research report is finished. The information you tell me will be used for purposes of this study and publications in academic journals only. If you have any questions or requests to me about the research and you part in it, I encourage you to ask me at any time before, throughout or after the interview.

Confidentiality

The information that the other caregivers who participate in this discussion give is confidential and private as well. Therefore I would like to ask you to keep their information private and not share it with anybody outside of this group discussion.

Contact

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Consent for tape-recording

I agree to be tape-recorded yes/no

If you decline to be tape-recorded, notes will be written down during discussion instead.

Consent for participating in the study

I have been given and have understood an explanation of this research project and I participate voluntary:

Project participant:

Signed: _____
Date: _____

Witness, when necessary:

Signed: _____
Date: _____

Appendix 6 – Informed consent form individual pretesting interviews for participants in Kisumu

CONSENT TO PARTICIPATION IN RESEARCH

Study: The effect of pictogram labels on caregivers' understanding of how and why to give antibiotic treatment for childhood pneumonia as instructed.

Background and purpose

You are asked to participate in a study on the effect of pictogram labels on caregiver's understanding of how and why to give antibiotic treatment for childhood pneumonia as instructed. Pictograms have been developed for treatment instructions of the antibiotic to treat childhood pneumonia. Because you have a child yourself child, I would like to interview you and hear your perceptions on these pictograms.

My name is Annemiek and I am public health researcher and a social psychologist. At the moment I am doing research for my master degree in 'International Community Health' for the University of Oslo in Norway.

It is my hope that when I finish my research here, your information can be used to improve the pictograms. I am an independent researcher and doing this out of my own interest. I do not work for any organization and I am not paid by anyone to do this research.

What is an interview?

To be interviewed means that we meet and talk. The interview may take up to one hour. I will use a tape recorder but you can refuse this and then I will take some notes instead. Since I do not speak your local language my assistant will be present to translate. I am interested in you telling me your story, and I respect what you know. I will listen and learn from you.

Voluntary participation

To participate is entirely voluntary. You should not feel pressured to discuss issues that you do not want to talk about. You can end the discussion at anytime without telling me why you chose to do so. There will be no consequences of this. I would like you to know that your identity will be confidential. Your name and exact age will not be written anywhere and will never be used in relation to the information you tell me. Instead you will be presented by a code such as 'Caregiver a'. The recordings will be deleted once my research report is finished. The information you tell me will be used for purposes of this study and publications in academic journals only. If you have any questions or requests to me about the research and you part in it, I encourage you to ask me at any time before, throughout or after the interview.

Contact

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Consent for tape-recording

I agree to be tape-recorded yes/no

If you decline to be tape-recorded, notes will be written down during discussion instead.

Consent for participating in the study

I have been given and have understood an explanation of this research project and I participate voluntary:

Project participant:

Signed: _____
Date: _____

Witness, when necessary:

Signed: _____
Date: _____

Appendix 7 – Checklist observations

Observation checklist

Observations	Mark (√) and /or comment
Pharmacist explain for what disease the medicine is being prescribed	
Pharmacist explains how to prepare the medicine: - add clean/boiled/treated water - till level or how much ml - shake	
Pharmacist demonstrate this with bottle	
Pharmacist explains the dose/how much to give	
Pharmacist demonstrate this with measuring cup on the bottle	
Pharmacist tells to give the medicine 3x a day: - in the morning, midday or evening, Or - every 8 hours	
Pharmacist tells to give for 5 days	
Pharmacist explains why to give for 5 days	
Pharmacist tell to pour left over medicine after 5 th day	
Pharmacist explain reasons why medicine has to be poured	
Pharmacist uses pictogram instructions when explaining the instructions on how to give medicine	
Pharmacist asks if patients understand or have any questions	
Patient asks questions during or after consultation	

Date: **Time:** **Location:** **Pharmacist:**

Attitude pharmacist/How does the pharmacist approach the patient?

.....
.....
.....

Attitude patient/How does the patient approach the pharmacist?

.....
.....
.....

Communication barriers, if any

.....
.....
.....

If given more than 1 drug: is it explained in same way or different? In what way same or different?

.....
.....
.....

Appendix 8 – Interview guide individual interviews, first version

Objectives:

- To assess perception of the symptoms of childhood pneumonia
- To assess how treatment was given
- To assess the reason for why treatment was given in the way it was
- To assess the understanding of the treatment instructions
- To assess perception of usefulness of the pictograms
- To assess how communication with health workers was experienced
- To assess perceptions of treatment of childhood pneumonia

Guide:

1. Introduction (explain purpose and ask how child is feeling now) and consent
2. What was wrong with your child? Has he/she suffered from it before?
Probe: What was it that made you seek care at health facility? How did you deal with the disease?
3. How did you treat the child?
Probe: How did you give treatment? When? How many times a day? How many days? What did you do with medicine after treatment? What was difficult when giving treatment? What was easy? What happened when you gave him/her treatment?
4. How did you decide to give the treatment this way?
Probe: In what way did the pictograms influence how you gave treatment? In what way did the health provider instructions influence the way you gave the treatment? In what way did past experiences influence the way you gave treatment?
5. Does your neighbor have a child less than 5 years? (If yes, how old, if no ask anyone else close to her and how old). If your neighbor's child had pneumonia and received a bottle of Amox syrup how would you advise her?
Probe: Could you explain me what the message is of the pictograms? (If she finds difficult start with could you tell me what you see, and then message). Is there anything in the pictures which you do not like? If yes, please show me, and tell me what you don't like. Is there anything which is difficult to understand? Please show me
6. How was the consultation with the health worker?
Probe: What did he/she do which you liked/found helpful? (probe for more than 1 thing) What did he/she do which you did not like? (Probe for more than 1 thing). How did he/she explained to you about the medicine? How did you like the way she explained how to give the medicine? What was it in his/her instructions which you found helpful? Was there anything which was difficult to understand from her explanation?

Appendix 9 - Interview guide individual interviews, revised version

Objectives:

- To assess what symptoms made the mother decide to take her child to the clinic and for what reason
- To assess perceptions of what disease she was treating
- To assess how treatment was given
- To assess the reason for why treatment was given in the way it was
- To assess the understanding of the treatment instructions
- To assess the understanding of the pictorial medicine instructions
- To assess perception of usefulness of the pictograms
- To assess how communication with health workers was experienced
- To assess learning on how to treat the symptoms

Guide:

1. Consent

2. What was wrong with your child?

Probe: Could you tell how the disease started and how you dealt with it? What was it that made you seek care at health facility? Has he/she suffered from it before?

3. How did you treat the child?

Probe: What treatment did you give? How did you give it? When? How many times a day? How many days? What did you do with medicine after treatment? What was difficult when giving treatment? What was easy? What happened when you gave him/her treatment?

4. Does your neighbor have a child less than 5 years? (If yes, how old, if no ask anyone else close to her and how old). If you neighbor's child has same symptoms as your child what would you advice her to do?

Probe: How would you advice her to give the Amoxicillin? How prepare? How many times a day? How much? For how many days? What to do when there is medicine left? What would you advice her to do if the child is feeling better after 3 days? What if child is not starting to feel better after treatment is finished? For what reason would you advice her this?

5. What is it that made you give the medicine the way you did?

Probe: Which instructions did you follow? In what way did your past experience influence how you gave treatment? In what way did the health provider influence the way you gave treatment? In what way did the pictograms influence the way you gave treatment? What do other mothers do?

6. What do you think about the pictogram instructions?

Probe: For what reason did/didn't you use the pictogram instruction? Could you explain me what the message is? (If difficult: first could you tell me what you see, then message, same as pretesting) Is there anything you like? In there anything you don't like? If used, in what way did you use instructions when administrating drug?

6. How was the consultation with the pharmacist?

Probe: What did he/she do which you liked/found helpful? (probe for more than 1 thing) What did he/she do which you did not like? (Probe for more than 1 thing). How did he/she explained to you about the medicine? How did you like the way she explained how to give the medicine? What was it in his/her instructions which you found helpful? Was there anything which was difficult to understand from her explanation?

Age:

Place:

Occupation:

Schooling:

Appendix 10 – FGD guide, FGD with caregivers who used pictorial instructions

Objectives:

- Explore if and in what way the pictograms changed understanding of the treatment instructions
- Explore if and how the pictograms played a role in adherence to the instructions
- Explore how communication with health provider/pharmacist was experienced
- Explore recommendations for possible future use of pictograms for medicine instructions
- Explore if the style of the pictograms for instructions has any influence on understanding how and why to give treatment

Guide

1. Hand out pictograms. Thanking for interviews and for coming to this discussion. Purpose is to discuss some of the things that came up during the interviews amongst each other, and hear your suggestions for how to use the pictograms in the future. Since you have all used the pictogram your input is very valuable. Feel free.

- First of all, how are your babies now?

2. Having used this pictogram when you gave Amoxicillin to your child, what can you say about using it?

Probe: how did they use it? Was it helpful? In what way? Difficulties? How improve?

Ask Annemiek if she has questions

3. Has the pictogram taught you anything new about the disease?

Probe; New learning symptoms? New learning disease? Past practice that has changed? For what reason? Change understanding of why you should adhere to the treatment?

Ask Annemiek if she has questions

4. What did you think before about the need to finish the course?

Probe: For what reason? On what was this based?

Ask Annemiek if she has questions

5. How did you experience consultation with pharmacist?

Probe: What did you find helpful? What would you liked to have more info about?

How do the pictogram instructions come into this?

Ask Annemiek if she has questions

6. Share PATH pictogram. Explain that they are developing Amox dispersibles just like Coartem and that they are developing pictograms for it.

- Give them first some time to look at the pictograms

- How would you use this to explain to neighbor? Ask to demonstrate

Probe: Easy? Difficult? For what reason?

Ask Annemiek if she has questions

7. Which pictograms do you prefer?

Ask for their preference step by step, so preparation, diagram how to take it,

pictograms of mother & child, bacterial load

Probe: For what reason? Does it matter? Would the style of the dispersible tab pictograms have any influence on how to give treatment is given? If yes, in what way? For what reason?

Ask Annemiek if she has questions

8. - Do you think this pictogram like these should be used with caregivers in the future?

Probe: For what reason? In what way?

Ask Annemiek if she has questions

9. Thank and appreciate.

Appendix 11 - FGD guide, FGD with caregivers who did not use pictorial instructions

Objectives:

- explore on what basis they decided how to give the treatment
- asses reasons for why they decide not to use the pictogram instructions
- Explore if and in what way the pictograms changed understanding of the treatment instructions
- Explore how communication with health provider/pharmacist was experienced
- Explore recommendations for possible future use of pictograms for medicine instructions
- Explore if the style of the pictograms for instructions has any influence on understanding how and why to give treatment

Guide

1. Introduction & Hand out pictograms

Thanking for interviews and for coming to this discussion. Purpose is to discuss some of the things that came up during the interviews amongst each other, and to understand better how and why they give medicines the way they do, and how they think mothers in the community can learn well how to give the best treatment/treatment in the best way. Feel free & input is much appreciated.

- First of all, how are your babies doing?

2. How did you give the medicine?

Probe: For what reason? How did you decide this?

Ask Annemiek if she has questions

3. You were given pictogram instructions by the pharmacist but decided not use it.

We would like to understand these reasons, to help us decide what to recommend to the clinic. For what reason did you decide not to use it?

Probe: For other mothers: should they just not use it? Or should we improve it so it becomes easier for you to use?

Ask Annemiek if she has questions

4. Having discussed these pictogram instructions when we came to visit, what can you say about them?

Probe: How did you understand? What was easy? What was difficult? Do you find them helpful? If yes, in what way?

Ask Annemiek if she has questions

5. Change in understanding instructions

Has the pictogram in any way changed the way you understand the treatment of the disease?

Probe; New learning symptoms? New learning disease? Past practice that has changed? For what reason? Change understanding of why you should adhere to the treatment?

Ask Annemiek if she has questions

6. Communication with health worker

How did you experience consultation with health worker/pharmacist?

Probe: What did you find helpful? What would you like to have more info about?

Ask Annemiek if she has questions

7. Share PATH pictogram. Explain that they are developing Amox dispersibles just like Coartem and that they are developing pictograms for it.

- Give them first some time to look at the pictograms

- How would you use this to explain to neighbor? Ask to demonstrate

Probe: For what reason?

Ask Annemiek if she has questions

8. Which pictograms do you prefer? Ask for their preference step by step, so

preparation, diagram how to take it, pictograms of mother & child, bacterial load

Probe: For what reason? Does it matter? Would the style of the dispersible tab pictograms have any influence on if and how to give treatment? If yes, in what way?

For what reason?

Ask Annemiek if she has questions

9. Now, I would like your opinion about something I have found during my interviews with x mothers in your community: All of you in this group have given reasons why you did not look at/use the pictorial instructions: Some of you say it was because you did not know it was helpful, some of you said because you thought it was nonsense, some of you said because you already knew, and some of you said it was because it is the pharmacist who should explain. It seems like nobody has managed to give the medicine in the way it is recommended for the child to get the best treatment, which is (xml) 3 times a day, for 5 days. In the group of women who did use the pictogram instructions, all of them in fact gave the medicine in the recommended way. What do you think about this?

Ask Annemiek if she has questions

10. Thank and appreciate

Appendix 12 – Discussion guide pharmacists

Objectives

- To share and reflect upon findings from observation consultation
- To share and reflect upon findings from interview with caregivers
- To assess the perception of the usefulness of the pictogram as a tool to work with instructions
- To assess recommendation for possible future use of pictograms for medicine instructions
- To assess if and how us being presence has influenced consultation in any way

Guide

1. Thank you for taking your time to have this interview with us. We would like to talk with you because we have been working with you since the start of this project and you have been giving out the pictogram instructions to clients who were given Amoxyl syrup. During this interview we would like you to comment and reflect upon some findings from the observation and the interviews. Your input is much appreciated, feel free.
2. We have noticed during the observation that you approach the patients in a humble way and that you talk nicely to them. This is also something that came up during the interview with the caregivers. What do you think about this?
3. We have also noticed during the observation that the instructions you give vary from client to client. Sometimes you give full instructions on how to prepare and give the medicine and demonstrate with the bottle, other times you just give a very brief explanation, and other times you only write 1x3. What do you think about this?
Probe: For what reason? For what reason difference in style of giving instructions?
4. During the interviews it came up that mothers prefer to have full explanation on how to prepare and give the medicine. This also has an influence on how they give the drug, what is not explained, such as numbers of days, is often where it goes wrong in giving the medicine. What do you think about this?
Probe: For what reason? Did you expect this? For what reason?
5. We followed up on 27 mothers and 1 father, during the interview it came up at 14 of them had used the pictogram and 14 did not. The ones who did not use the pictogram instructions did not give the medicine in the recommended way, the ones who used the pictogram instructions did give in the recommended way.
What do you think about this?
Probe: For what reason? Did you expect this? For what reason?
6. For majority mothers the bacterial load explains why they have to adhere to treatment and it encouraged them to really give according to the instructions. What do you think about this?
Probe: For what reason? Is this info told at the clinic? If yes, in what way? If no, for what reason?
7. When you gave out the pictogram instruction you did not really say much about them, and a couple of times you forgot to give them. For what reason did you used the

pictogram the way you did?

Probe: Anything about the pictogram? Anything about how we introduced the pictogram? For what reason?

8. The mothers who did not use the pictogram said this was because when they got the pictogram they thought it was nonsense, did not know it could help them, and it is the pharmacist job to explain the full instructions. However, once they've looked at it during the interview they liked them and it help them with understanding the instructions. They think that they would have used the pictogram if you instructed them to read it before giving the medicine because it could help them. What do you think about this?

Probe: For what reason?

9. Do you think pictograms like these should be used in the future?

Probe: For what reason? In what way? Is there anything we could do to make it easier/better for you to work with them?

10. Often we were with you in the pharmacy while you were helping clients. Did our presence in any way influenced your work?

Probe: In what way? For what reason? Did it influence the way you talked to the patients? For what reason?

11. Thank and appreciate

Appendix 13 – Caregivers’ demographics

		Caregivers who used pictorial instructions	Caregivers who did not use pictorial instructions
<i>Age</i>	Mean	26.3	27.07
	Median	28	24.5
	Highest	33	49
	Lowest	16	19
<i>Schooling</i>	Mean	form 1	class 8
	Median	form 1	class 8
	Highest	form 4	form 4
	Lowest	class 7	class 6
<i>Occupation</i>	Non	6	9
	Market	5	4
	Small business	2	0
	Student	0	1
<i>Clinic</i>	Nyang’ande	4	7
	Rabuor	9	7

Appendix 14 – Ethical approval Norway



Region: REK sør-øst	Saksbehandler: Silje U. Lauvrak	Telefon: 22845520	Vår dato: 03.07.2013	Vår referanse: 2013/1007/REK sør-øst D
			Deres dato: 28.05.2013	Deres referanse:

Vår referanse må oppgis ved alle henvendelser

To Ane Haaland

2013/1007 Forståelse av visuelle instruksjoner for bruk av antibiotika

In reference to your application reviewed by the Committee on the 13th of June 2013.

Institution responsible: University of Oslo

Chief Investigator: Ane Haaland

Project description

In Kenya, where this study will be conducted, 17% of child deaths are caused by pneumonia. However, deaths are preventable when treatment is given in time. In 2011 WHO changed recommendations for treatment for childhood pneumonia to dispersible Amoxicillin as first line treatment. In Kenya, first line treatment is still Septrin, but the Government is in the process of changing this and follow the WHO guidelines. For Amoxicillin, pictograms are being developed for medication instructions. Studies have shown that using pictograms can have a positive influence on adherence to antibiotic instructions, but there is a gap in understanding what it is exactly that makes a difference for the patients taking the medicine in the way it is prescribed. The aim of the project is to explore the influence of pictograms on caregivers' understanding of how and why to give antibiotics as instructed, and adherence to the instructions.

Committee's considerations

The Committee reviewed the application during its meeting on 13 June 2013. The project was assessed in accordance to the Norwegian Research Ethics Act of 30 June 2006 and Act on medical and health research (the Health Research Act) of 20 June 2008 for the regional committees for medical and health research ethics.

The aim of the project is to explore the influence of pictograms on caregivers' understanding of how to give antibiotics as instructed, as well as adherence to the instructions. The project will give insight in how treatment instructions are given and how pictograms can help caregivers understand the antibiotic instructions, rather than new knowledge about health and disease. The project is therefore not within the remit of the Health Research Act, which applies only to research activities that generate new knowledge about health and disease.

The project can be performed without approval by the Regional Committee for Medical Research Ethics.

The Committee's decision

The project is not within the remit of the Health Research Act. The project can be performed without approval by the Regional Committee for Medical Research Ethics.

The decision of the committee may be appealed to the National Committee for Research Ethics in Norway.

The appeal should be sent to the Regional Committee for Research Ethics in Norway, South-East D. The deadline for appeals is three weeks from the date on which you receive this letter.

Besøksadresse:
Gullhaugveien 1-3, 0484 Oslo

Telefon: 22845511
E-post: post@helseforskning.etikkom.no
Web: <http://helseforskning.etikkom.no/>

All post og e-post som inngår i saksbehandlingen, bes adressert til REK sør-øst og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK sør-øst, not to individual staff



Yours Sincerely,

Stein A. Evensen
Prof. dr. med.
Chair of the Regional Committee for
Medical Research Ethics of Southern Norway
(P.P.)
Section D

Silje U. Lauvrak
Adviser

Copy to: ane.haaland@medisin.uio; universitetsdirektor@uio.no

Appendix 15 – Ethical approval Kenya



KENYATTA NATIONAL HOSPITAL
APPROVED
30th OCT 2013
ETHICS & RESEARCH COMMITTEE

UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P.O. BOX 19676 Code 00202
Telegrams: varsity
(254-020) 2726300 Ext 44355

KNH/UON-ERC
Email: uonknh_erc@uonbi.ac.ke
Website: www.uonbi.ac.ke

KENYATTA NATIONAL HOSPITAL
P.O. BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/342 Link: www.uonbi.ac.ke/activities/KNHUoN 30th October 2013

Annemiek Hel
Institute of Health and Society
[University of Oslo](http://www.uio.no)

Dear Annemiek

RESEARCH PROPOSAL: THE INFLUENCE OF PICTOGRAMS ON CAREGIVERS' UNDERSTANDING OF HOW AND WHY TO GIVE ANTIBIOTICS AS INSTRUCTED (P448/08/2013)

This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and **approved** your above proposal. The approval periods are 30th October 2013 to 29th October 2014.

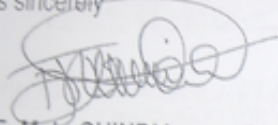
This approval is subject to compliance with the following requirements:

- Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH/UoN ERC before implementation.
- Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH/UoN ERC within 72 hours of notification.
- Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH/UoN ERC within 72 hours.
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
- Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.
- Submission of an *executive summary* report within 90 days upon completion of the study
This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

For more details consult the KNH/UoN ERC website www.uonbi.ac.ke/activities/KNHUoN.

"Protect to Discover"

Yours sincerely




PROF. M. L. CHINDIA
SECRETARY, KNH/UON-ERC

c.c. Prof. A.N.Guantai, Chairperson, KNH/UoN-ERC
The Deputy Director CS, KNH
The Principal, College of Health Sciences, UoN
AD/Health Information, KNH
Supervisors: Ane Haaland, Institute of Health and Society, University of Oslo
Co-supervisor: Prof.Christoph Gradmann, Institution of Health and Society, University of Oslo

Appendix 16 – NSD approval

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES



Harald Hårfagre gate 29
N-5007 Bergen
Norway
Tel: +47 55 58 21 17
Fax: +47 55 58 96 50
nsd@red.uib.no
www.nsd.uib.no
Org nr: 985 321 884

Ane Haaland
Institutt for helse og samfunn
Universitetet i Oslo
Postboks 1130 Blindern
0318 OSLO

Vår dato: 14.06.2013 Vår ref: 34727 / 3 / KH Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 11.06.2013. Meldingen gjelder prosjektet:

34727	<i>The effect of pictogram labels on caregivers' understanding and adherence to antibiotic instructions. A qualitative study</i>
Behandlingsansvarlig	Universitetet i Oslo, ved institusjonens øverste leder
Daglig ansvarlig	Ane Haaland
Student	Annemiek Hell

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

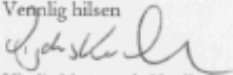
Personvernombudets tilrådning forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

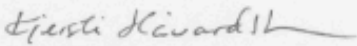
Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 30.06.2014, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen


Vigdis Namtvedt Kvalheim


Kjersti Håvardstun

Kontaktperson: Kjersti Håvardstun tlf: 55 58 29 53
Vedlegg: Prosjektvurdering
Kopi: Annemiek Hell, Waldemar Thranes gate 40a, 0171 OSLO

Avdelingskontorer / District Offices
OSLO NSD, Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47 22 85 52 11. nsd@iuh.no
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TROMSØ NSD, SVU, Universitetet i Tromsø, 9037 Tromsø. Tel: +47 77 64 43 36. nsd@iuhv.uib.no

Appendix 17 – Research Permit Kenya


REPUBLIC OF KENYA

National Commission for Science, Technology and Innovation
RESEARCH CLEARANCE PERMIT
Serial No. A 611
CONDITIONS: see back page

CONDITIONS

1. You must report to the County Commissioner and the County Education Officer of the area before embarking on your research. Failure to do that may lead to the cancellation of your permit
2. Government Officers will not be interviewed without prior appointment.
3. No questionnaire will be used unless it has been approved.
4. Excavation, filming and collection of biological specimens are subject to further permission from the relevant Government Ministries.
5. You are required to submit at least two(2) hard copies and one(1) soft copy of your final report.
6. The Government of Kenya reserves the right to modify the conditions of this permit including its cancellation without notice.

PAGE 2 **PAGE 3**
Research Permit No. NCST/RCD/12A/013/129
Date of issue 11th November, 2013
Fee received KSHS, 30,450

THIS IS TO CERTIFY THAT:
Prof./Dr./Mr./Mrs./Miss/Institution
Annemiek Hell
of (Address) Institute of Health and Society
University Of Oslo.
has been permitted to conduct research in

Location
District
Kisumu **County**

On the topic: The influence of pictograms on caregivers' understanding of how and why to give antibiotics as instructed.


Applicant's Signature **For: Secretary**
National Commission for Science, Technology & Innovation

for a period ending: 31st July, 2014.

Appendix 18 – Informed consent form individual interviews

CONSENT TO PARTICIPATION IN RESEARCH

Study: The effect of pictogram labels on caregivers' understanding of how and why to give antibiotic treatment for childhood pneumonia as instructed.

Background and purpose

You are asked to participate in a study on the effect of pictogram labels on caregiver's understanding of how and why to give antibiotic treatment for childhood pneumonia as instructed. Because your child has been prescribed Amoxicillin and pictograms have been given for medication instructions I would like to interview you and hear your experiences.

My name is Annemiek and I am public health researcher and a social psychologist. At the moment I am doing research for my master degree in 'International Community Health' for the University of Oslo in Norway.

It is my hope that when I finish my research here, your information can be used to improve how medicine instructions are given. I am an independent researcher and doing this out of my own interest. I do not work for any organization and I am not paid by anyone to do this research.

What is an interview?

To be interviewed means that we meet and talk. The interview may take up to one hour. I will use a tape recorder but you can refuse this and then I will take some notes instead. Since I do not speak your local language my assistant will be present to translate. I am interested in you telling me your story, and I respect what you know. I will listen and learn from you.

Voluntary participation

To participate is entirely voluntary. You should not feel pressured to discuss issues that you do not want to talk about. You can end the interview at anytime without telling me why you chose to do so. There will be no consequences of this. I would like you to know that your identity will be confidential. Your name and exact age will not be written anywhere and will never be used in relation to the information you tell me. Instead you will be presented by a code such as 'Caregiver a'. The recordings will be deleted once my research report is finished. The information you tell me will be used for purposes of this study and publications in academic journals only. If you have any questions or requests to me about the research and you part in it, I encourage you to ask me at any time before, throughout or after the interview.

Contact

Researcher:

Annemiek Hell

United Oasis, Ojijo Oteko Rd, Kisumu, Kenya

0718221068

Email: a.j.m.hell@medisin.uio.no

Ethics & Research committee:
KNH/UON-ERC secretariat
P O BOX 20723-00202, Nairobi, Kenya
(254-020)2726300 Ext 44102
Email: uonknh_erc@uonbi.ac.ke

Consent for home-visit

I agree for the researcher to visit my home to conduct the interview yes/no

In case you don't want to have the interview at your home we will conduct the interview at the following location: _____ (write down preferred location)

Consent for tape-recording

I agree to be tape-recorded _____ yes/no

If you decline to be tape-recorded, notes will be written down during discussion instead.

Consent for participating in the study

I have been given and have understood an explanation of this research project and I participate voluntary:

Project participant:

Signed: _____
Date: _____

Witness, when necessary:

Signed: _____
Date: _____

Appendix 19 – Informed consent form FGD

CONSENT TO PARTICIPATION IN RESEARCH

Study: The effect of pictogram labels on caregivers' understanding of how and why to give antibiotic treatment for childhood pneumonia as instructed.

Background and purpose

You are asked to participate in a study on the effect of pictogram labels on caregiver's understanding of how and why to give antibiotic treatment for childhood pneumonia as instructed. Because your child has been prescribed Amoxicillin and pictograms have been given for medication instructions I would like to invite you to this focus group to hear your experiences.

My name is Annemiek and I am public health researcher and a social psychologist. At the moment I am doing research for my master degree in 'International Community Health' for the University of Oslo in Norway.

It is my hope that when I finish my research here, your information can be used to improve how medicine instructions are given. I am an independent researcher and doing this out of my own interest. I do not work for any organization and I am not paid by anyone to do this research.

What is a focus group discussion?

A focus group discussion is a group conversation where you will share your experiences about childhood pneumonia, treatment and the pictograms for instructions with other caregivers who had recently given their children medication for childhood pneumonia as well. The discussion may take up to two hours. I will use a tape recorder but you can refuse this and then I will take some notes instead. Since I do not speak your local language my assistant will be present to translate. I am interested in you sharing your story, and I respect what you know. I will listen and learn from you.

Voluntary participation

To participate is entirely voluntary. You should not feel pressured to discuss issues that you do not want to talk about. You can end the discussion at anytime without telling me why you chose to do so. There will be no consequences of this. I would like you to know that your identity will be confidential. Your name and exact age will not be written anywhere and will never be used in relation to the information you share. Instead you will be presented by a code such as 'Caregiver a'. The recordings will be deleted once my research report is finished. The information you tell me will be used for purposes of this study and publications in academic journals only. If you have any questions or requests to me about the research and you part in it, I encourage you to ask me at any time before, throughout or after the interview.

Confidentiality

The information that the other caregivers who participate in this discussion give is

confidential and private as well. Therefore I would like to ask you to keep their information private and not share it with anybody outside of this group discussion.

Contact

Researcher:

Annemiek Hell

United Oasis, Ojijo Oteko Rd, Kisumu, Kenya

0718221068

Email: a.j.m.hell@medisin.uio.no

Ethics & Research committee:

KNH/UON-ERC secretariat

P O BOX 20723-00202, Nairobi, Kenya

(254-020)2726300 Ext 44102

Email: uonknh_erc@uonbi.ac.ke

Consent for tape-recording

I agree to be tape-recorded yes/no

If you decline to be tape-recorded, notes will be written down during discussion instead.

Consent for participating in the study

I have been given and have understood an explanation of this research project and I participate voluntarily:

Project participant:

Signed: _____

Date: _____

Witness, when necessary:

Signed: _____

Date: _____

Appendix 20 – Amoxicillin treatment course given by caregivers

Treatment course given by caregivers who used the pictorial medicine instructions

Respondent Id; child age	Dose given at home by caregiver	Correct dose Yes/No	3x day Yes/No	No. of days medicine given							Throw remaining syrup Y/N	Correct regime Yes/No	Correct dose+regime Yes/No	Comments
				1	2	3	4	5	> 5					
C, 1 year	5 ml	yes	yes						x		yes	yes	Yes	
D, 4 years	10	yes	yes			x					Non left	no	no	Medicine got finished at 3 rd day
G, 2 years	5 ml	Yes	Yes						X		Yes	Yes	Yes	
H, 4 months	½ teaspoon (2.5ml)	yes	yes						x		yes	yes	yes	
J, 3 years	Teaspoon (5ml)	yes	yes						x		yes	yes	Yes	
M, 3 years	5 ml	Yes	Yes						x		yes	Yes	Yes	
Q, 3 years	5ml	Yes	yes						x		yes	yes	Yes	
S, 2 years	5 ml	Yes	Yes						X		Yes	Yes	yes	
U, 7 months	2.5 ml	Yes	Yes						X		No	yes	yes	
X, 2 years	5 ml	Yes	Yes						X		Yes	Yes	yes	
Z, 2 years	5 ml	Yes	yes						X		Yes	Yes	yes	
AA, 2 years	5 ml	Yes	Yes						X		Yes	Yes	yes	
AB, 3 months	Teaspoon	No	Yes	X							No	No	No	Child vomiting
Total incorrect actions taken		1									3	2	2	
Total correct actions taken		12	13								10, but 1 had no left	11	11	

Treatment course given by caregivers who did not use the pictorial medicine instructions

Respondent Id; child age	Dose given at home by caregiver	Correct dose	3x day Yes/No	No. of days medicine given							Throw remaining syrup Y/N	Correct regime Yes/No	Correct dose+regime Yes/No	Comments
				1	2	3	4	5	> 5					
A, 5 months	2.5ml	Yes	yes			x					Non left	no	no	Gave to other child as well at same time
B, 1.5 years	5 ml	Yes	yes							x	Non left	no	No	
E, 1.5 years	10 ml	No	yes			x					Non left	no	no	Medicine got finished 3 rd day
F, 3.5 years	5 ml	No	yes							X	Non left	No	No	
I, 4 months	5 ml	No	yes			x					no	no	no	Child better day 3
K, 8 months	Teaspoon (5ml)	No	yes						x		yes	yes	no	children gave sometimes
L, 2 years	Teaspoon	Yes	yes							x	Non left	no	no	
N, 1 month	Teaspoon	No	yes							x	Non left	no	no	Gave to another child as well
O, 9 months	½ Teaspoon (2.5ml)	Yes	yes							x	Non left	no	no	
P, 2.5 years	tablespoon	No	yes			x					yes	no	no	Child better day 3
R, 4 months	Big spoon	No	No, 2x				x				Non left	no	no	Gave till finished
W, 6 months	Teaspoon	no	yes				4				no	no	no	
Y, 1.5 years	½ teaspoon	no	yes						x		yes	yes	No	
AC, 5 years	teaspoon	no	yes						x		yes	yes	no	
Total incorrect actions taken		10	1								2	11	14	
Total correct actions		4	13								12, but 8 had no	3	0	

Appendix 21 – Amoxicillin treatment instructions given by the pharmacists

Pharmacists' instructions for caregivers who used the pictorial medicine instructions

Caregiver ID	Pharmacist	Oral preparation	Preparations demonstrated	Oral 3x1	Written 3x1	Dose	5 days	Finish dose	Pour	Pictograms amoxyl inst.	Pictograms help	Comments
C, 1 year	B, Ravour	x			X		x			X		
D, 4 years	B, Ravour	x	x		x					X		
G, 2 years	B, Ravour			x	x	x		X				
H, 4 months	Bo, Nyang	x			x							
J, 3 years	Bo, Nyang	X	x		x	x						Asked if new how to finish
M, 3 years	Bo, Nyang	x			x	x		X		x	X	
Q, 3 years	S, Ravour	x		x	x							
S, 2 years	B, Ravour	x	x		x	x		X		x		
U, 7 months	B, Ravour	x			x					x	X	
X, 2 years	M, Nyang			x	x	X				X		
Z, 2 years	M, Nyang	x			x		X					
AA, 2 years	S, Ravour	x			x						X	
AB, 3 months	M, Nyang	x		x	x			x		x	X	Pharm. Got really angry at patient before AB
Total inst. received		11	3	4	13	5	2	4		7	4	Total 8 got instructions about pictogram

Pharmacists' instructions for caregivers who did not use the pictorial medicine instructions

Caregiver ID	Pharmacist	preparation	Preparations demonstrated	Oral 3x1	Written 3x1	Dose	5 days	Finish dose	Pour	Pictograms amoxyl inst.	Pictograms help	Comments
A, 5 months	B, Ravour	X	x		x			X		X	X	
B, 1.5 years	B, Ravour	x		x	X	X						
E, 1.5 years	B, Ravour	x			x		X					
F, 3.5 years	Bo, Nyang			x	x			X				
I, 4 months	Bo, Nyang	X			x			X		X		
K, 8 months	B, Ravour	X	x	x	X	X						
L, 2 years	B, Ravour				X					X	X	Asked if she knew how to use med
N, 1 month	M, Nyang	X	x		x	x	X					
O, 9 months	Bo, Nyang	X			x			x		x	X	
P, 2.5 years	M, Nyang	x		x	X			X			X	
R, 4 months	B, Ravour				X	x		X		X		
W, 6 months	S, Ravour	X			X							
Y, 1.5 years	M, Nyang	x			X	x				x	X	
AC, 5 years	S, Ravour	X	x	x	x					x	X	
Total inst. received		10	4	5	14	5	2	5	0	7	6	In total 8 told about pictogram

Appendix 22 – Helles Fund

UiO : Faculty of Medicine
University of Oslo

Annemiek Hell

Date: 8th April 2013
Your ref.:
Our ref.: Ragnhild Beyrer

Dear Annemiek Hell

Ivar Helles' Foundation

You have applied for economical support for fieldwork from Ivar Helles' Foundation. The committee has finalized their work and they found to grant your application with

NOK 8.650,-

If you need the money as an advance, you should contact Ragnhild Beyrer latest in the middle of May in order to make arrangements for transferring the money. You should also read carefully the enclosed instructions how your expenses should be documented and how the statement should look when you return to University of Oslo for submitting of receipts and finalizing the given grant.

One of the committee members, Camilla Hansen, who is and socialanthropologist has read all the applications, is willing to give some feedback thorough e.mail. No discussion, only some advices which you can use in your work. If interested, her e.mail is camilla.hansen@medisin.uio.no

Sincerely yours

Johanne Sundby (s)

Camilla Hansen(s)

Edvard Hauff (s)

Copy: Gunnar Bjune



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