From first symptom to treatment: a qualitative study of cervical cancer patients in Ethiopia

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Referat

Gebärmutterhalskrebs ist der zweithäufigste Krebs von dem Frauen in Äthiopien betroffen sind. 2012 wurden 7095 neue Fälle von Gebärmutterhalskrebs in Äthiopien gemeldet[1]. Diese Zahl macht deutlich, dass Maßnahmen gegen Gebärmutterhalskrebs getroffen werden müssen, besonder da die Inzidenz von Gebärmutterhaskrebs gut mittels Impfungen und Vorsorgeuntersuchungen verringert werden kann. Doch um ein funktionierendes System mit Präventionsmaßnahmen aufzubauen, ist es wichtig, die Situation vor Ort genau zu kennen. Daher ist das Ziel dieser Arbeit, die Situation von Patientinnen mit Gebärmutterhalskrebs in Äthiopien so genau wie möglich zu beschreiben, ihren Weg vom ersten Symptom bis zum Beginn der Therapie zu untersuchen und dabei Hindernisse, Probleme und motivierende Aspekte herauszuarbeiten.

Dabei wurden zwei verschiedene Methodiken verwendet. Zum einen wurden eine systematische Literaturrecherche durchgeführt, um zu verstehen, welche Aspekte von Gebärmutterhalskrebs in Äthiopien und seinen Nachbarländern bereits beleuchtet wurden. Zum anderen wurden Patientinnen mit Gebärmutterhalskrebs in Äthiopien eingehend intervied, um ihre Geschichte und Erfahrungen zu untersuchen und auszuwerten.

Es wurde deutlich, dass viele Probleme für Patientinnen existieren. Sowohl Patientinnen als auch Mitarbeiter im Gesundheitssystem haben wenig Wissen über Gebärmutterhalskrebs, seiner Symptome und Therapiemöglichkeiten. Dies führt sowohl zu Fehlinterpretationen, Fehldiagnosen und Falschüberweisungen. Diese und weitere logistische, finanzielle und soziale Aspekte führen zu einem langwierigen und kompliziertem Weg. Zusätzlich zeigte sich, dass Familie und Freunde eine große Rolle für die Patientinnen spielen. In der Mehrzahl der Fälle waren diese eine starke Unterstützung und halfen den Patientinnen den komplizierten Weg zu bestreiten. Allerdings zeigte sich auch, dass diese eine negative Rolle spielen können.

Zukünftige Aufklärungscampagnen bei äthiopischen Frauen, aber auch bei Mitarbeitern des Gesundheitssystems, könnten helfen, einige der größten erkannten Hürden auf dem Weg von erstem Symptom zum Beginn der Therapie zu verringern. Dabei müsste vorsichtig vorgegangen werden um Patientinnen vor Diskrimminierung und Ausgrenzung zu schützen. Zusätzlich könnte die Einbindung der Patientinnen in den Diagnostik- und Therapie-Prozess helfen, ihnen Ängste zu nehmen aber auch die Weitergabe von Informationen über Gebärmutterhalskrebs an andere Frauen in Äthiopien zu ermöglichen.

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[1] WHO International Agency for Research on Cancer (2012); Globocan 2012

I Content

II Abbreviations

AA	Addis Ababa
ASR	Age Standarized Ratio
CD4	Cluster of differentiation
DHS	Demographic and Health Survey
GAVI	Global Alliance for Vaccines and Immunization
HIV	Human Immunodeficancy Virus
HPV	Human Papilloma Virus
HR	High risk
HS	Health station
NCD	Non communicable diseases
PAP	Papanicolaou
PL	Primary level
PS	Private Sector
SL	Secondary level
STD	Sexually transmitted disease
TAH	Tikur Anbessa Hospital
TBC	Tuberculosis
TL	Tertiary level
UNDP	United Nations Developement Program
UTI	Urinary tract infection
VIA	Visual inspection with acetic acid
WHO	World Health Organization

1 Introduction

In the past, I have often found women in developing countries to be in a very difficult situation when they face illness: they are scared of not being able to fulfill their role as a housewife when they seek medical care; they have little medical literacy; they depend on their husbands for support; socially and financially. Especially those women suffering from chronic diseases found themselves in a situation where they had to go through many years of treatment never knowing if they would survive their disease. These experiences showed me the importance of research in developing countries especially with women, to help future patients gain more support and to help countries to tackle the problems occurring inside their health system.

Ethiopia is the second biggest country in Sub-Saharan Africa with 92 million citizens (The Worldbank). Despite a significant acceleration of its economic growth rate in recent years, it still ranks on the bottom of the Human Development Index, 173 rd out of 186 countries (UNDP).

Women in Ethiopia are especially vulnerable within the Ethiopian community. Literacy rates of women are still lower than those of men, with 51% of women having no formal education compared to 30% of men. Furthermore, first marriage at an average age of 16.5 years and first birth at 19.2 years occur much earlier than in men and in the majority of cases women depend on their husbands' income (DHS Programm, 2011).

When asked about common diseases in Ethiopia, most people in Europe will think of infectious diseases like malaria, tuberculosis and human immunodeficiency virus (HIV). People in Ethiopia will answer in a similar way. In recent years a lot of effort was made by the Ethiopian government to tackle this problem (Federal Democratic Republic of Ethiopia, 2010). A three- tier system was set up to treat patients with the focus on communicable diseases and mother and child care. Referral takes place from the primary and wide-spread level, to a secondary level and ends at the tertiary level in a specialized hospital (WHO). This system is supposed to send patients suffering from a serious disease, through only a few visits to a hospital where they can gain appropriate treatment.

With mortality rates of infectious diseases decreasing (WHO, 2013), the incidence of non-communicable diseases (NCD) is rising, accounting for 30% of death in Ethiopia in 2014 (WHO) and new challenges arise for the health system: How can NCDs be detected? Where can patients gain appropriate treatment? How can these diseases be prevented? Is sufficient medicine available? How can patients be supported on this long road of suffering? Cancer is one major group of these NCDs. When I asked Ethiopians what they think of cancer, most of them replied that cancer cannot be treated and that people die from it. This answer illustrates the perception of cancer in Ethiopia.

The Globocan study (WHO International Agency for Research on Cancer, 2012) from 2012 named 61 thousand new cases of cancer and 45 thousand cancer deaths in Ethiopia. With 41 thousand of these cases being female, women are hit especially hard by this disease. The most common cancer for women is breast cancer and the second most common cervical cancer with crude incidence rate of 31.5 and 17.3 per 1000 and the number of new cases 13,000 and 7,000 per year respectively.

Considering that pre-cancerous lesions can easily be detected and treated and that they develop over a long time frame, such a high incidence rate has to be alarming. 85% of the cancer deaths occur in less developed countries proving that a greater effort must be made to tackle this problem. *"In developing countries, limited access to effective screening means that the disease is often not identified until it is further advanced and symptoms develop. In addition, prospects for treatment of such late-stage disease may be poor, resulting in a higher rate of death from cervical cancer in these countries"* (WHO). Furthermore, treatment availability is scarce in Ethiopia. For advanced stages of cervical cancer radiotherapy is the common means of treatment. However, only one radiotherapy center exists in the whole country, which further delays start of treatment for the patients.

This study aims to describe the situation which women in Ethiopia face, when they are suffering from cervical cancer. The pathway which patients followed from the moment they experienced their initial bodily changes until they started receiving radiotherapy in Tikur Anbessa Hospital (TAH) is described in this study. Different motivating and demotivating aspects will be pointed out and perception of cervical cancer will be examined.

Two different ways were chosen to approach the topic. First of all, existing literature was reviewed to find out what is already published regarding the perception of cervical cancer in Ethiopia. In order to achieve as precise a picture as possible of the existing literature, data from other countries in Eastern Africa was also studied. The second approach aimed at cervical cancer patients themselves in Ethiopia. Interviews with women diagnosed with cervical cancer were performed in order to find out more about the personal perception of those suffering from this disease and to explore problems as well as positive aspects of their pathway to treatment. Consequently, all information gained is received from patients who managed to receive treatment. The group of women, which might be large, who are suffering from cervical cancer, but never received therapy did not come to word in this study. This qualitative approach was chosen deliberately in order to get a perspective on this topic as broad as possible. It enables patients to bring forward those issues which seem important for them and guide the path of this study with their answers. Thus, an in- depth understanding of the path from first symptom to treatment of cervical cancer patients in Ethiopia will be described.

2 Objectives

This study aims to describe the situation of cervical cancer patients in Ethiopia in order to inform future target interventions. The following steps were taken in order to explore the topic from a wide angle:

1. To review literature on perception of cervical cancer in Ethiopia and Eastern Africa;
2. To explore the pathway to treatment of cervical cancer patients in Ethiopia;
3. To assess barriers on the pathway to treatment for cervical cancer patients in Ethiopia;
4. To assess triggers for action on the pathway to treatment;
5. To explore patients´ knowledge on cervical cancer both before and after diagnosis;
6. To describe perceived signs associated with cervical cancer and lay interpretation of these;
7. To discuss the different means of influence people from the community had on cervical cancer patients in Ethiopia;
8. To describe the role of health institutions besides the public health care system.

3 Methods

This project focuses on women with cervical cancer in Ethiopia. It is done as part of a cooperation between Martin Luther University Halle, Germany and Addis Ababa University, Ethiopia. This cooperation aims to enhance knowledge regarding female cancer in Ethiopia. I worked closely together with staff from radiotherapy department of TAH, Addis Ababa (AA) public health school and the gynecology department of Martin Luther University Halle.

Two different approaches were chosen to gain information on cervical cancer patients in Ethiopia: firstly, a systematic literature reviews and secondly a qualitative study with cervical cancer patients who received treatment in Ethiopia.

3.1 Literature Review

In order to summarize existing knowledge regarding cervical cancer perception in Ethiopia a systematical literature review was done and repeated regularly. The final literature review was done on the 26/10/16.

3.1.1 Approach

In order to approach existing literature systematically the issue of cervical cancer in Ethiopia was narrowed down to locating those publications which are closely related to this study. This was done by determination of inclusion and exclusion criteria. Since the scope of this publication is focused on the perception of cervical cancer and barriers to accessing treatment, the following were chosen to be inclusion criteria: clinical presentation, knowledge, alternative medicine, delay, vaccination, vulnerability and treatment options. Studies which focused on Human Papilloma Virus (HPV) genotypes were excluded.

Using Pubmed, titles, abstracts, key words and, if necessary, complete articles, were screened for inclusion and exclusion criteria.

3.1.2 Ethiopia

Existing literature was looked for using the search term: cervical cancer Ethiopia. Main facts from all publications were gathered and discussed. To gain further knowledge regarding the trend inside the publications a closer look was also put on the quantity of publications over the years and the topic which were put main focus on over the time.

3.1.3 Neighboring countries

Afterwards, the literature review was extended to those countries neighboring Ethiopia, by using the search term: cervical cancer connected with each country respectively. First of all, I looked at

Djibouti, Eritrea and Somalia which form, together with Ethiopia, the Horn of Africa and share a joint history. Since no publications from these countries exist, I further extended the search to Tanzania, Kenya, Uganda, Rwanda and Burundi. Similar to the countries of the Horn of Africa, no publications were found from Burundi, but publications from the other four countries do exist. This data, I wanted to use to locate other data to compare with existing data from Ethiopia, but also to extend the scope of perspective. These countries have started to implement vaccination and screening programs and thus, much can be learned from their experiences, their challenges, and their achievements.

Main facts from all publications were gathered and discussed. To gain further knowledge regarding the trend within the publications, a closer look was also taken at the quantity of publications over the years and the topics mainly focused on over the time period.

3.2 Qualitative approach

A qualitative explorative approach was chosen, to investigate the issue of perception of cervical cancer in Ethiopia with a broad perspective. Qualitative studies are rare in medical science but it bears the advantage of openly studying a topic and the adaptation of the study to upcoming data.

Furthermore it is a subjective approach, where views and worries of individuals are examined. It does not aim to generalize a problem but to openly explore one and then to help shape future research (Hesse-Biber & Leavy, 2011). Even though interesting literature on the issues of cervical cancer was found, this data still did not offer a full picture of cervical cancer patients in Ethiopia. Therefore, a qualitative approach seemed to be the most fitting method.

3.2.1 Ethics

Ethical approval was gained from the AA University Medical Faculty Institutional Review Board. Approval was given for a series of studies regarding “Epidemiologic Survey of Ethiopian Urban and Rural areas on Breast Cancer and other Gynecologic Cancer Prevalence and Clinical Epidemiology” made by participants of the cooperation between AA University and Martin Luther University.

A copy of the ethical approval is found in the Appendix 1.

Since the planned interviews touch very sensitive topics, “*researchers must ensure the rights, privacy, and welfare of the people and communities that form the focus of their studies.*” (Berg, 2001).

Therefore, data was anonymized to ensure that the privacy of each participant is maintained and that the data cannot be used against the participant, even if they bring up negative facts regarding the doctors treating them or the health care system in itself. Also, great care was taken that no participant was forced to take part in the study or got the feeling that taking part would bring them any kind of benefit regarding their visit to the hospital. A copy of the form of consent can be found in appendix 2. This form was read out to the patient and if necessary further explained.

3.2.2 Data Collection

Interviews

Data for this study was collected in in-depth semi-structured interviews. The interviewer was guided by an interview guideline throughout the interview, but had the ability to pursue the topics brought up by the patients, as suggested by Flick (Flick, 2009). In this setting, it is important that the interviewer has good knowledge about the topic. In that way, he is sensitized and open for new issues. It is even more important, however, that the interviewed patients feel safe and trust the interviewer, so that she is able to open herself to the questions.

Interview Guideline

After I gathered the main findings from the literature review and general ideas regarding perception of cervical cancer, I discussed these points with people involved; for example, doctors and people working in public health. Those issues which seemed to be the most pressing and important for understanding the topic were gathered and formed the basis of the interview guideline (figure 1).

These issues should picture different areas which can affect help seeking behavior. Therefore, the procedure with its referral system and accessibility played a big role, as well as the emotional and personal effects arising from such a disease.

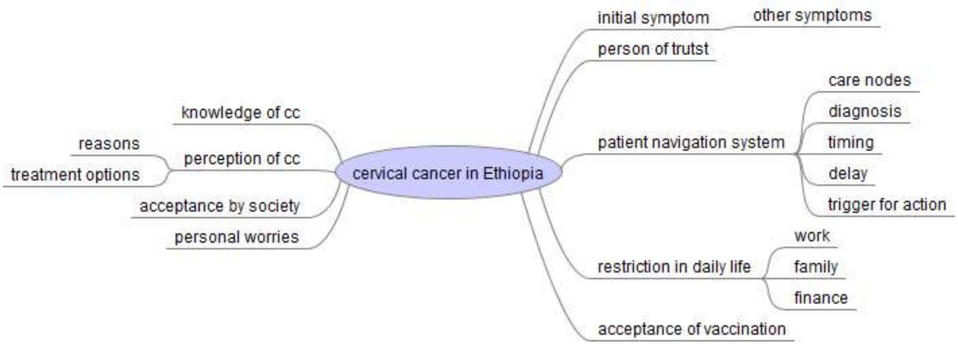


Figure 1 - Issues regarding perception of cervical cancer forming the basis for the interview guideline

"When conducting interviews it is always a question of balance between openness (for the interviewed person) and structure (given by the interviewer)" (Flick, 2009). For the research questions of this study it is important that patients can answer openly, describing their situation and feeling the freedom to bring up new topics and their concerns. On the other hand, it is important to cover the main research topics in order to have a wide base for analysis. Therefore, I decided that the main part of the interview should be semi-structured.

The interview guideline only consisted of bullet points designed to help the interviewer remember which different issues should be talked about. In this part of the interview questions should be open and a conversation between interviewer and patient should be established. Therefore, no prewritten questions existed, since these could break off an ongoing conversation.

In the second part of the interview specific questions regarding the socio-demographic background and reproductive history of the patient were asked. A copy of the interview guideline can be found in appendix 3.

Preparation of Interviews

Thomas Addisie was chosen to conduct the interviews. He has a master degree in socio-anthropology and good experience in conducting interviews for qualitative studies. He previously worked in the medical field with female cancer. Being Ethiopian he is fluent in Amharic, the common language used in the interviews and is also familiar with culture and tradition in Ethiopia.

In order to obtain consistency during the interviews, I decided that Mr. Addisie should conduct all interviews and would also be responsible for transcription and translation.

Before the interviews started I conducted a training session with Mr. Addisie in order to introduce him to the aim of the study and to make him familiar with cervical cancer and its clinical presentation.

Following points were covered in the training:

- General introduction to cervical cancer
- Cervical cancer in Ethiopia, clinical presentation, therapy options
- Overview existing literature
- Explanation of the study background
- Aim of the study
- Interview techniques (Stringer, 2007)
- Going through the interview guideline.

Testing Interviews

Three patients with gynecologic cancer, undergoing in-patient treatment at radiotherapy department of TAH, were asked to participate in a test trial for the research. All three agreed and talked openly about their disease history. Where necessary, topics, like vaccination against HPV, were dropped, if the patient was not suffering from cervical cancer. This trial was done in order to check if a male interviewer is accepted, if questions are understood and also to see how openly patients share their experience.

It became obvious that patients had difficulties to give precise answers on certain topics, especially when asked for time intervals or age. This also led to uncertainty regarding chronological occurrence of signs or visits to health stations. We learned that it was easier for patients to remember certain events when they could talk freely about their pathway to treatment, instead of asking specific questions. Therefore, we decided that conducting open interviews was the best means to archive answers. However, we realized that uncertainty would remains and that this fact has to be taken into account when results were interpreted.

Conducting interviews

In order to create a confidential atmosphere interviews were conducted in a separate room or, if that was not possible, in a separate space where patients had the feeling of privacy.

Language of interviews was Amharic. If patients did not speak Amharic they were asked if a close relative could work as a translator. This was done in three cases.

In one case the patient was not aware of her situation, so the family stepped in and explained what had happened to her mother.

Patients were first introduced to the study and its aim and what to expect (time, structure), before they were asked for their written content and tape recording started.

Interviews were started with an open question regarding their initially perceived symptom. From this point on, the patients could freely tell their own story. I decided to start with the open part of the interview so that trust could be built between interviewer and patient. Also, content of the interviews was not narrowed down by those topics which we thought to be interesting beforehand. Only if a topic was not covered during the ongoing conversation, Mr. Addisie was asked to bring up the subject.

Interviews lasted between 17 and 43 minutes, depending on the communicativeness of the patients. Some patients were enthusiastic about sharing their experiences, underlining things that must be changed and others were uncommunicative, answering in short sentences, waiting for the interviewer to lead the conversation.

Interview logbook

Important findings from each interview were noted as well as specific reactions and emotions. Furthermore, the International Federation of Gynecology and Obstetrics (FIGO) state when diagnosed in TAH was copied from the patient´s file.

Review of interview content

In order to adapt the interviews to the topics mentioned during the interviews, each interview was followed by a short analysis. This was conducted to identify the main issues mentioned, new topics and also difficulties. Therefore, the bullet point list was adapted each time to the acquired data and the procedure allowed the data itself to lead the way forward. In the process of these analyses it was found that more attention should be put on the timing between different health nodes and the referral system since patients answers were often ambiguous; that discrimination was a topic often mentioned; and that the topic of vaccination could not be raised, since patients had not enough knowledge to give an uninfluenced opinion about it.

Transcription and translation

Each audio recording of an interview was literal transcribed and then translated into English, following Transcription Conventions as suggested by Flick in his book “An introduction to qualitative research” (Flick, 2009). Distinctive features like loud laughter or crying was marked specially.

The translated text were checked for understanding difficulties and logical breaks and then double checked with the original recording.

5 interviews were chosen to be transcribed and translated by an external person. The 2 translations were then compared with each other in order to see if different interpretation or description occurred.

3.2.3 Analysis of data

In order to analyze the data, the amount of data had to be reduced to the important issues and then organized. This was done using content analyzing strategies. The organization aspect was not only important for a structured analysis, but also for other people to understand the process whereby a high level of quality can be obtained.

Theory of Content Analysis

Content analysis is described by Krippendorf as *“a research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use”* (Krippendorff, 2013).

Many different approaches to qualitative content analysis exist. But as Margrit Schreier (Schreier, 2014) has said, the content-structured analysis can be seen as the basis for content analysis. Those methods explained by others, (Hsieh, 2005; Boyatzis, 1998), are just variation of it. All of them have in common that they are based on a category system, in which important quotes can be organized in a comprehensible and reasonable way (Schreier, 2014).

The category system is the central point in quantitative content analysis (Mayring, 2014).

A category system is set up in a certain hierarchy, starting with a big group which is then separated into more detailed subgroups. On top is the family. A family gathers sub categories about one certain issue. In this study one example would be: road to treatment.

1st subcategories describe a certain aspect of a family. So in this case, a 1st subcategory of “road to treatment” would be “timing”. This subcategory can be separated further into different timing intervals: e.g. “appraisal interval”.

Thus, with each subcategory the topic it relates to becomes more defined, till in the end quotes can be clearly associated with one specific topic.

The main difference in the various approaches to content analysis is the decision how categories are created. Mayring suggest a deductive approach, where categories are created before data collection on the basis of literature review and previous experience.

The other approach is an inductive approach (Thomas, 2006), where categories are created following the gained data.

Recent publication support a mixed approach where inductive and deductive methods are combined (Schreier, 2014). I chose such a mixed approach for the following reasons:

- I used literature review before the start of data collection to build a guideline for the interviews. This guideline already offers me some categories.(deductive)
- Data which can be used prior to this study is limited since I am working on a under-researched topic, thus it is important to reconsider the category system and also include new categories if necessary (inductive)

Therefore, analyzing the obtained data I followed the tools described by Schreier (Schreier, 2014). In short, I followed the following points

- Get-to-know material
- Development of main categories from research question and interview guideline
- Looking for fitting quotes
- Development of subcategories and definitions
- Coding of complete material with continuous adaptation of category system
- Result presentation, Interpretation and answer of research question

In figure 2 an overview of the categories and subcategories used in this work can be seen. All those marked in blue were created in a deductive way and those marked with orange in an inductive way.

The deductive categories were discussed when the interview guideline was put together with colleagues involved with cervical cancer in Ethiopia. The inductive categories were decided together with Thomas Addisie, both of us going through the collected data, looking for interesting quotes and then building new categories and discussing these.

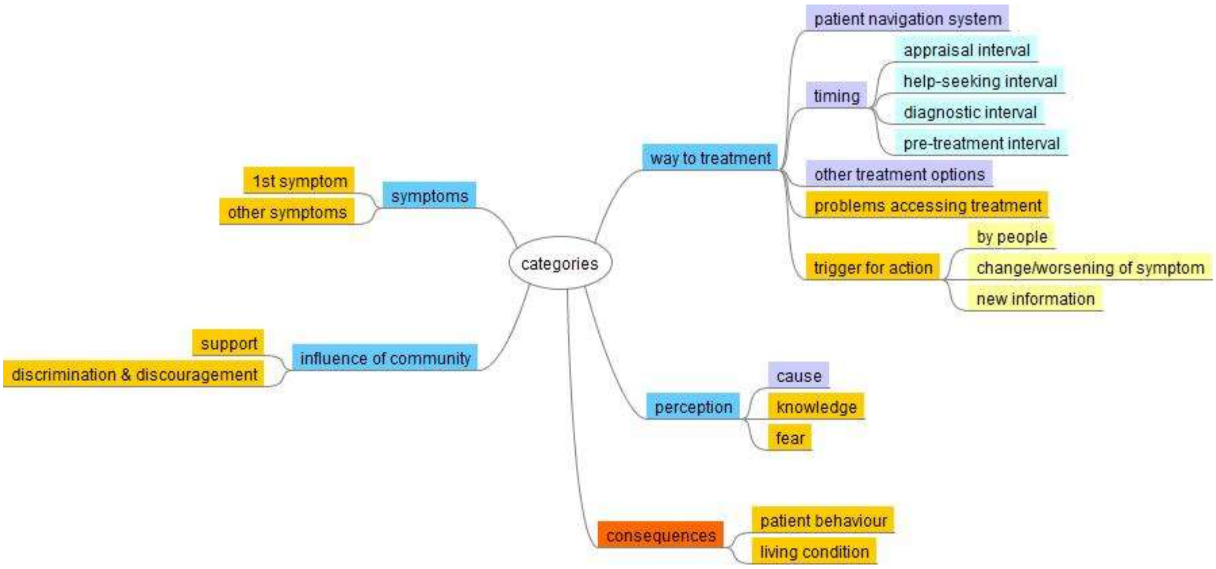


Figure 2- Overview of categories used for analyzing data; blue group: deductive categories, orange group: inductive categories

Computer Software for Analysis

In recent years computers have started to play a crucial role in content analysis. Mayring pointed out in which way computer software supports researchers in their task:

- It works as an assistant, supporting and making easier the steps of text analysis on screen
- It works as a documentation center, recording all steps of analysis of all interpreters, making the analysis comprehensible and replicable
- It offers links to quantitative analysis. (Mayring, 2000)

In this study MAXQDA Version 10 was used to support the analysis process.

After processing the raw text data, the texts were important into MAXQDA and then quotes were referred to their appropriate category. Variables about the socio-demographic factors and reproductive history were marked from the interviews and copied into a list.

3.2.4 Quantitative part of Analysis

This is a qualitative approach to cervical cancer and therefore, focus was put on the issues patients talked about. It was their subjective perspective and each explanation was seen as important and was thus taken into consideration. The objective of this study is to understand what influences the patients´ pathway to treatment and not to see how many of them found themselves in a certain situation.

However, quantitative data occurred along the path, mainly time intervals and visits to health stations. Out of curiosity, I decided to run some correlations of certain categories to see if these show any connection. But first of all, these correlations were done on data, which, as I already discussed, was not reliable. Secondly, no well-founded hypothesis exists, which can be proven by a correlation. And thirdly, the correlations did not arrive at a result which pointed to a clear direction.

Due to all these reasons, I decided to show those numbers which came up from the interviews, but I did not publish any further analysis.

4 Results

This chapter is divided into two parts, literature review and qualitative approach. Results from the literature review are found in 3.1 and its subcategories and everything from 3.2 is related to the qualitative approach.

4.1 Literature Review

The literature review was last done in October 2016, aiming to find literature regarding perception of cervical cancer and the pathway of treatment of cervical cancer patients in Ethiopia and its neighboring countries.

4.1.1 Publication used

Overall 263 publications were screened regarding cervical cancer in Ethiopia and its neighboring countries. Figure 3 gives an overview of those publications screened and used.

Regarding cervical cancer in Ethiopia, I found 43 publications published in the last 10 years. After application of inclusion and exclusion criteria 15 publications were involved in the literature review.

Afterwards, I extended the search for Ethiopia´s neighboring countries; using the search term cervical cancer for those countries I applied inclusion and exclusion criteria for the found literature. Overall, I used 22 from 87 publications regarding cervical cancer in Kenya; 5 from 14 publications regarding cervical cancer in Rwanda; 14 from 46 publications regarding cervical cancer in Tanzania and 21 from 73 publications regarding cervical cancer in Uganda.

Altogether I utilized 77 publications from a total of 263 (figure 3).

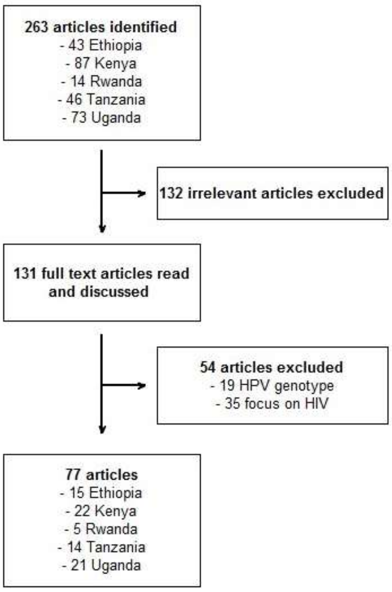


Figure 3– Overview of publications found and used for literature review

In table 1 those publications used in the literature review are displayed organized by country and year of publication. Looking at the total number of publications, the issue of cervical cancer´s perception and understanding may have come more into the scope of science. However, it has to be observed if this trend will be verified.

Table 1 -— Publications used listed by country and year of publications

		East Africa				
Year	Ethiopia	Kenya	Rwanda	Tanzania	Uganda	Total
2016	4	1		1	4	10
2015	7	9	1	4	7	28
2014	1	5	2	1	4	13
2013	2	3	1	1	3	10
2012	1	3	1	5	2	12
2011		1		1	2	4
Total	15	22	5	13	22	77

4.1.2 Cervical cancer in Ethiopia

Studies published on cervical cancer in Ethiopia focused on a wide range of issues associated with cervical cancer and looked at the topic from many different angles. An overview of these publications gives table 2.

One study published in 2015 showed that cervical cancer patients in Ethiopia face a lot of **challenges** (Tadesse, 2015). Challenges were found in the health care system, leading to a long delay, psychologically, like fear and negative social attitude and economical with the inability to cover expenses for treatment and accommodation.

Costs faced by cervical cancer patients was another issue described *(Hailu and Mariam 2013).* Estimated mean outpatient cost was $ 407.2 with the largest share in direct outpatient costs, which consists of expenditure for consultation of a physician, investigations and medicine.

Finding **risk factors** for obtaining cervical cancer was aimed at by Bezahib and his colleges. They made an unmatched case control study with woman diagnosed with cervical cancer and women without. They found that older woman, woman with more than one husband, woman of husband with more than one wife in life, women with more than 4 children and age of more than 25 years at full term delivery were at greater risk of developing cervical cancer (Bezabih et al., 2015). The above mentioned study by Tadesse also looked at this problem and found that poverty and socio-cultural practices like early marriage, high parity and in certain extend polygamy increased the vulnerability to cervical cancer.

Knowledge regarding cervical cancer was another topic closely looked at. Interviewing rural population in northern Ethiopia it was found that even though people had heard of cervical cancer knowledge was low. People were not aware of associated risk factors, signs and symptoms of cervical cancer (Getahun et al., 2013). Another study published in 2016 showed that 50 % of women in Northeast Ethiopia were knowledgeable of cervical cancer (Mitiku et al., 2016). Sufficient knowledge was associated with formal education and household income.

Low knowledge was found to be one of existing **barrier** for patients to seek help for cervical cancer (Birhanu et al., 2012). Furthermore, in the same study was found, that perceived benefits of modern treatment was low and many difficulties in accessing treatment were found. Women suffering from cervical cancer had to face discrimination and exclusion from society.

But knowledge is not only low amongst Ethiopian population. Assessing the knowledge regarding cervical cancer amongst **health care workers** in Ethiopia was the aim of a study conducted in 2012 (Goedken et al., 2015). Even though health professionals had heard of cervical cancer, knowledge about etiology and associated risk factors was low. With less than 40% of the health care workers ever having performed any kind of cervical cancer screening the necessity of prevention was not understood. Reasons named for this were lack of training and lack of resources. Similar observations were seen in another study with only half of the health professionals being able to name signs and symptoms of cervical cancer and less than a quarter knew about the association between HPV and development of cervical cancer (Wondimu, 2015).

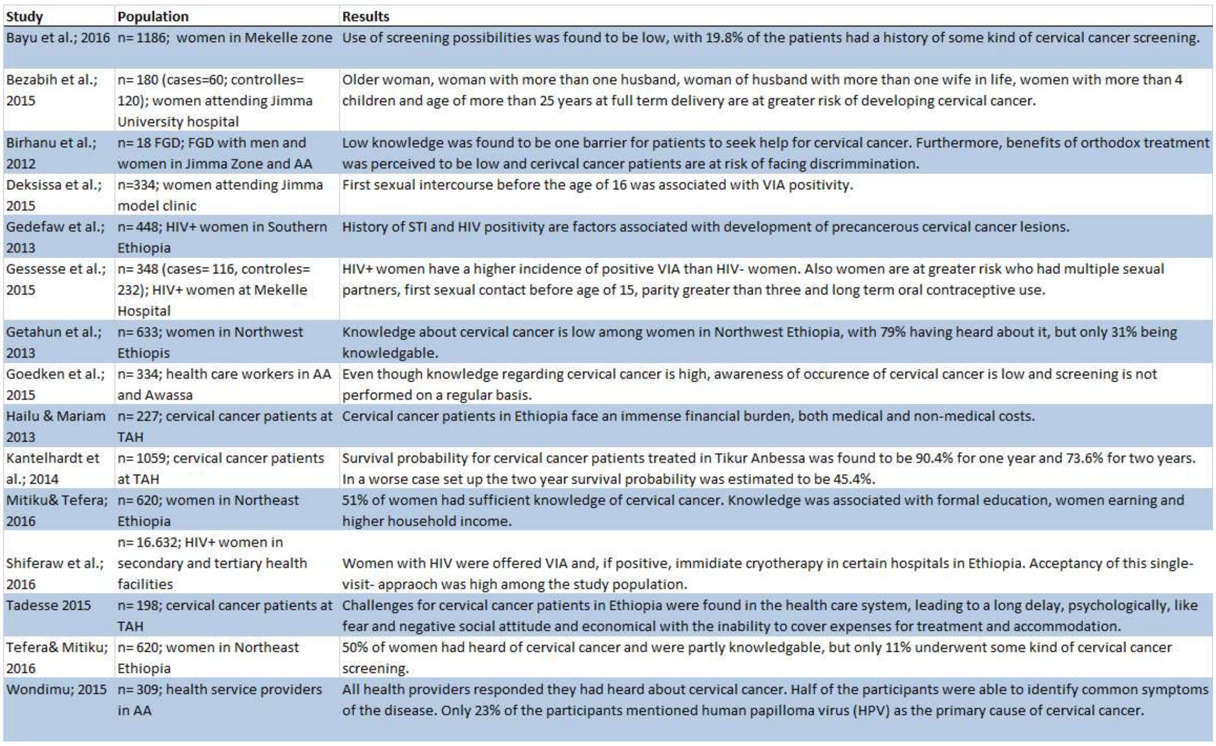
Other studies tried to find predictors for positive results of a visual inspection with acetic acid (**VIA**). Predicting an association between HIV and risk of developing cervical cancer two studies tested HIV positive woman and found that an associated risk for developing precancerous lesions were a low CD4 cell count and a high number of sexual partners (Gessesse et al., 2015). In another study it was found that HIV + women had a much higher incidence rate than HIV – women for precancerous lesions (Gedefaw et al., 2013). A higher incidence of precancerous lesions was also found in women with multiple sexual partners, first sexual contact before age of 15, parity greater than three and long term oral contraceptive use. A third study conducted in south west Ethiopia found that first sexual intercourse before the age of 16 was an independent factor associated with development of positive screening results (Deksissa et al., 2015). A study, assessing the single-visit-approach set up for HIV+ women in Ethiopia, found that acceptability was high among the study population (Shiferaw et al., 2016).

Use of screening possibilities was another issue looked at (Bayu et al., 2016). Findings were that overall **screening uptake** was low amongst the study population, only 19.8% had a history of cervical cancer screening. Associated factors for undergoing screening procedures were found to be: Age, history of multiple sexual partners, history of sexually transmitted disease, HIV zero status, over all knowledge of cancer and screening, perceived susceptibility to develop cancer. Another study found that women in Northeast Ethiopia had a history of some kind of cervical cancer screening was 11% (Tefera & Mitiku, 2016). However, this screening uptake was much higher than that stated in other publications, which was assumed to be around 1 % (Gakidou et al., 2008; WHO).

Treatment outcome was another topic looked at (Kantelhardt et al., 2014). Survival probability for cervical cancer patients treated in TAH was found to be 90.4% for one year and 73.6% for two years. In a worse case set up the two year survival probability was estimated to be 45.4%.

Looking through the conclusions of all these studies it was found that a majority highlights the need of implementation of screening programs including screening and vaccination possibilities, starting awareness campaigns and extension of existing treatment possibilities.

Table 2 – publications regarding cervical cancer in Ethiopia used for literature review



Study	Population	Results
Bayu et al.; 2016	n= 1186; women in Mekelle zone	Use of screening possibilities was found to be low, with 19.8% of the patients had a history of some kind of cervical cancer screening.
Bezabih et al.; 2015	n= 180 (cases=60; controlles= 120); women attending Jimma University hospital	Older woman, woman with more than one husband, woman of husband with more than one wife in life, women with more than 4 children and age of more than 25 years at full term delivery are at greater risk of developing cervical cancer.
Birhanu et al.; 2012	n= 18 FGD; FGD with men and women in Jimma Zone and AA	Low knowledge was found to be one barrier for patients to seek help for cervical cancer. Furthermore, benefits of orthodox treatment was perceived to be low and cerivcal cancer patients are at risk of facing discrimmination.
Deksissa et al.; 2015	n=334; women attending Jimma model clinic	First sexual intercourse before the age of 16 was associated with VIA positivity.
Gedefaw et al.; 2013	n= 448; HIV+ women in Southern Ethiopia	History of STI and HIV positivity are factors associated with development of precancerous cervical cancer lesions.
Gessesse et al.; 2015	n= 348 (cases= 116, controles= 232); HIV+ women at Mekelle Hospital	HIV+ women have a higher incidence of positive VIA than HIV- women. Also women are at greater risk who had multiple sexual partners, first sexual contact before age of 15, parity greater than three and long term oral contraceptive use.
Getahun et al.; 2013	n= 633; women in Northwest Ethiopis	Knowledge about cervical cancer is low among women in Northwest Ethiopia, with 79% having heard about it, but only 31% being knowledgable.
Goedken et al.; 2015	n= 334; health care workers in AA and Awassa	Even though knowledge regarding cervical cancer is high, awareness of occurence of cervical cancer is low and screening is not performed on a regular basis.
Hailu & Mariam 2013	n= 227; cervical cancer patients at TAH	Cervical cancer patients in Ethiopia face an immense financial burden, both medical and non-medical costs.
Kantelhardt et al.; 2014	n= 1059; cervical cancer patients at TAH	Survival probability for cervical cancer patients treated in Tikur Anbessa was found to be 90.4% for one year and 73.6% for two years. In a worse case set up the two year survival probability was estimated to be 45.4%.
Mitiku& Tefera; 2016	n= 620; women in Northeast Ethiopia	51% of women had sufficient knowledge of cervical cancer. Knowledge was associated with formal education, women earning and higher household income.
Shiferaw et al.; 2016	n= 16.632; HIV+ women in secondary and tertiary health facilities	Women with HIV were offered VIA and, if positive, immidiate cryotherapy in certain hospitals in Ethiopia. Acceptancy of this single-visit- appraoch was high among the study population.
Tadesse 2015	n= 198; cervical cancer patients at TAH	Challenges for cervical cancer patients in Ethiopia were found in the health care system, leading to a long delay, psychologically, like fear and negative social attitude and economical with the inability to cover expenses for treatment and accommodation.
Tefera& Mitiku; 2016	n= 620; women in Northeast Ethiopia	50% of women had heard of cervical cancer and were partly knowledgable, but only 11% underwent some kind of cervical cancer screening.
Wondimu; 2015	n= 309; health service providers in AA	All health providers responded they had heard about cervical cancer. Half of the participants were able to identify common symptoms of the disease. Only 23% of the participants mentioned human papilloma virus (HPV) as the primary cause of cervical cancer.

4.1.3 Cervical cancer in Eastern Africa

Lynette Denny describes the problem with cervical cancer in Africa as follows*: "Treatment of cervical cancer in Africa is hampered by the lack of diagnostic and treatment facilities, lack of healthcare infrastructure and poor pathology services. Further, there is a significant brain drain of trained healthcare workers in Africa that exacerbates the problem. Cancer is becoming an increasingly important public health problem as more people live longer."* (Denny & Anorlu, 2012)

This explanation shows that similar problems arise when looking at cervical cancer in Africa. Therefore, expanding the perspective by looking at other countries in Africa can help to learn from their problems and experiences, but also show ways which can help to tackle upcoming problems.

4.1.3.1 *Kenya, Tanzania, Rwanda, Uganda*

Publication regarding cervical cancer in Kenya, Tanzania, Rwanda and Uganda cover similar topics than those already described in the chapter `Cervical cancer in Ethiopia´. While Rwanda (Binagwaho et al., 2012) was the first country in Africa who successfully implemented a vaccination and screening program, Uganda (Banura et al., 2012) is running the first test programs and Tanzania (Watson-Jones et al., 2012) and Kenya (Friedman et al., 2014) prepare for a vaccine implementation running their first pilot studies. Ethiopia has also started their first trial vaccination program in cooperation with the GAVI in 2015 (WHO, 2015). Thus, looking at the experiences from their neighboring countries, Ethiopia can learn from them.

Even though a high acceptability of **vaccine implementation** exists, use of vaccination programs is lower than expected in Kenya. (Vermandere et al., 2015) Reasons found are concerns regarding side effects, especially infertility, barriers accessing vaccination camp, financial burden and concerns from partner or possible concern of future partners. These concerns were also raised in other studies conducted in Kenya (Friedman et al., 2014; Watson-Jones et al., 2015) and Tanzania (Cunningham et al., 2015; Remes et al., 2012). Therefore, prior education and sensitization campaigns seem to be a major factor for a successful vaccine implementation. Also involvement of teachers as vaccine promoters could help to tackle misunderstanding and concerns. (Vermandere et al., 2014)

In Rwanda 93% coverage of target population (227.246 girls) was achieved by a school based approach with inclusion of the community to also vaccine those girls not present at school and a nationwide sensitization campaign prior to program start. (Binagwaho et al., 2012)

Screening uptake is still low amongst women in Eastern Africa. Higher screening usage was associated with women being educated and those who were knowledgeable regarding cervical cancer and prevention possibilities. (Lyimo & Beran, 2012; Kahesa et al., 2012; Morema et al., 2014) Furthermore, a negative attitude of spouses regarding cervical cancer screening had a negative influence on screening usage. (Kileo et al., 2015) Knowledge of men in Kenya regarding cervical cancer was very low and a positive screening result of their partner would be upsetting for them. (Rosser et al., 2014)

However, it was shown that acceptability of screening programs was high among women. Besides their spouses´ opinion other obstacles which kept women from using screening methods were unawareness, high cost and long travelling distances. (Cunningham et al., 2015) Self-sampling possibilities were especially favored among women. (Rositch et al., 2012)

In order to improve screening uptake an improvement in screening services in primary health care level would be beneficial. (Rosser et al., 2015) Furthermore, more skilled health workers and a better access to screening services are necessary to increase screening uptake. (McCree et al., 2015)

Those women, who participated in screening programs and were tested positive, underwent following **treatment procedures** in the majority of cases. (Gard et al., 2014)

From those countries which were part of this literature review, Rwanda was the one which has the most detailed plan in order to tackle cervical cancer. They implemented a national strategic plan for cervical cancer and besides their vaccination program they also implemented a screening program: this consists of HPV DNA test followed by VIA and if necessary concluded colposcopy and biopsy. (Binagwaho et al., 2013)

Barriers in cervical cancer management were discussed in 3 studies. (Kivuti-Bitok et al., 2013; Mwaka et al., 2013; Ngutu & Nyamongo, 2015) Challenges were found on the patient side with a large number of patients presenting an advanced stage of cancer, low knowledge regarding cervical cancer and its prevention and treatment possibilities, discomfort and fear of pain. Patients reported about fear of stigmatization, difficulties of accessing health center, an immense financial burden and a lack of knowledge regarding clinical presentation of cervical cancer. However, also on the side of health care providers challenges were found: lack of specialized training, lack of knowledge and skills, difficulties in disclosure of diagnosis, poor attitude towards patients and screening. Furthermore, it was found that health facility lack supplies and skilled workers. Also, it was found that health facilities are difficult to reach.

One study looked at the **pathway to treatment** of patients with cervical cancer in Uganda. (Mwaka et al., 2015) First symptoms described were abnormal vaginal bleeding, offensive vaginal discharge and abdominal pain. Symptoms were often attributed to physiological bodily changes and common illnesses, like sexually transmitted diseases (STDs). Often patients started looking for help when they started to perceive symptoms as life threatening. But also after accessing the health system misdiagnosis was common and delayed start of treatment.

Cervical cancer patients´ **survival rate** was low in Kenya, with a two-year survival prediction below 20%. (Maranga et al., 2013) *"Cervical cancer is preventable yet poverty, poor education, lack of cancer awareness coupled with an absence of regular screening programs, late patient presentation, sub-optimal diagnosis and treatments are major factors contributing to the alarmingly low survival rate of cervical cancer patients in Kenya."*

Mobile phones were found to be one source for improving knowledge on cervical cancer. (Kivuti-Bitok et al., 2012) Even though internet usage was low amongst study patients, due to missing access or lack of knowledge, patients saw a great potential in using mobile phones to spread awareness regarding cervical cancer.

4.2 Qualitative approach

From this point on, results from the interviews are presented and the different subcategories are discussed separately.

4.2.1 Study population

From February till May 2014 cervical cancer patients at TAH Radiotherapy department were randomly asked if they are willing to participate in this study.

TAH is the only Hospital which offers radiotherapy in Ethiopia. Thus, all patients with advanced cases of cervical cancer have to come to this hospital in order to get adequate care. Therefore, I was able to find patients from all over Ethiopia with different socio-cultural backgrounds at one location.

Overall, 71 patients diagnosed with cervical cancer were asked to participate. Of those, 19 didn't want to take part in the study, 5 couldn't be interviewed due to language barriers, and 7 could not be found after they had consented. Therefore, 40 interviews were conducted (figure 4).

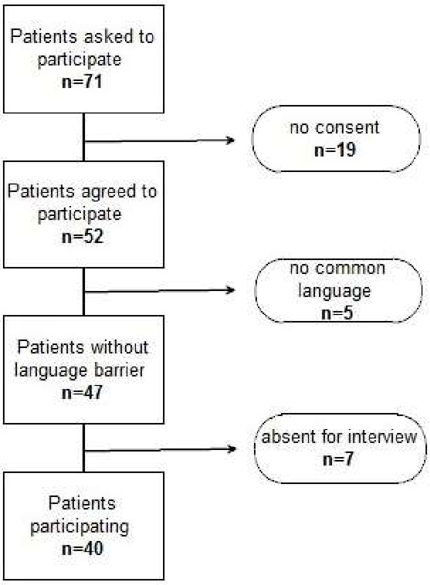


Figure 4– Quantity of participating women and reasons for none participation

4.2.2 Characteristics of study population

An overview of the characteristics of the study population can be found in table 3.

Age ranged between 29 and 74 years with an average of 52 years and a median age of 55. Postmenopausal were 28 (70%) of the women by the time they experienced their first sign (Table 3). Women participating came from a wide area of Ethiopia, from the mountains in the north to urban Addis Ababa to the flat south. They represented seven different ethnicities with the majority being Amhara (22; 55%), Oromo (7; 17.5%) and Tigray (5; 12.5 %). These are also the biggest in Ethiopia as counted in the census (Federal Democratic Republic of Ethiopia, 2007) from 2007 with Oromo (34.5 %), Amhara (27 %) and Tigray (6 %). The average distance from their place of residence to Addis Ababa was 195 km. The distance was calculated using Google maps. If the place of residence could not be found the first visited health post was used. 13 (32.5%) women lived in Addis Ababa by the time they were diagnosed. The furthest place of residence is in Mahila, 829 km away from Addis Ababa. 22 (55%) of the women live in an urban settlement. Figure 5 shows the region of residence of patients participating.

Literacy was low among study population with only 10 (25%) having been to school more than 4 years. The majority of women (27; 68%) did never go to school and only 3 (8%) of the women had a higher educational degree.

25 (63%) were married and lived together with their husband at the time of the interview, 13 (33%) were divorced or widowed and thus lived alone and 2 (5%) were never married in their live. Women had an average of 4.7 children, ranging from 0 to 10. None of the women had a planned abortion but 11(27.5%) women experienced one or more spontaneous abortions.

When diagnosed with cervical cancer in TAH 21 (53%) of the women had FIGO state II, 15 (38%) FIGO state III and 4 (10%) FIGO IV.

The following classification was used in TAH when interviews took place:

I –	Limited to cervix
II –	Extension to uterus/ parametria/ vagina
III –	Extension to pelvic side wall and/ or lower third of vagina
IV –	Extension to adjacent organs or beyond true pelvis

Table 3 – Characteristics of study population

Age	<50	14	35%
	>= 50	26	65%
	Mean age +- SD	51.93 +-10.44	
	Median	55	
	Range	29 - 74	
Education	little (<grade 5)	27	68%
	>= grade 5	10	25%
	N/A	3	8%
Residence	urban	22	55%
	rural	18	45%
Distance to AA	< 50 km	14	35%
	50 - 150 km	8	20%
	150 - 500 km	12	30%
	> 500 km	5	13%
	Mean distance +- SD	195.44 +- 222.63	
	Median	127	
	range	0 - 829	

Maritial statur	married	25	63%
	divorced/widow	13	33%
	single	2	5%
Parity	<=3	15	38%
	> 3	25	63%
	Mean +- SD	4.7 +-2.78	
	Median	4	
	range	0-10	
FIGO	I	0	
	II	21	53%
	III	15	38%
	IV	4	10%
Menopause	yes	28	70%
	no	9	23%
	n/a	3	8%
Therapy	before	13	33%
	during	13	33%
	after	13	33%
	n/a	1	3%

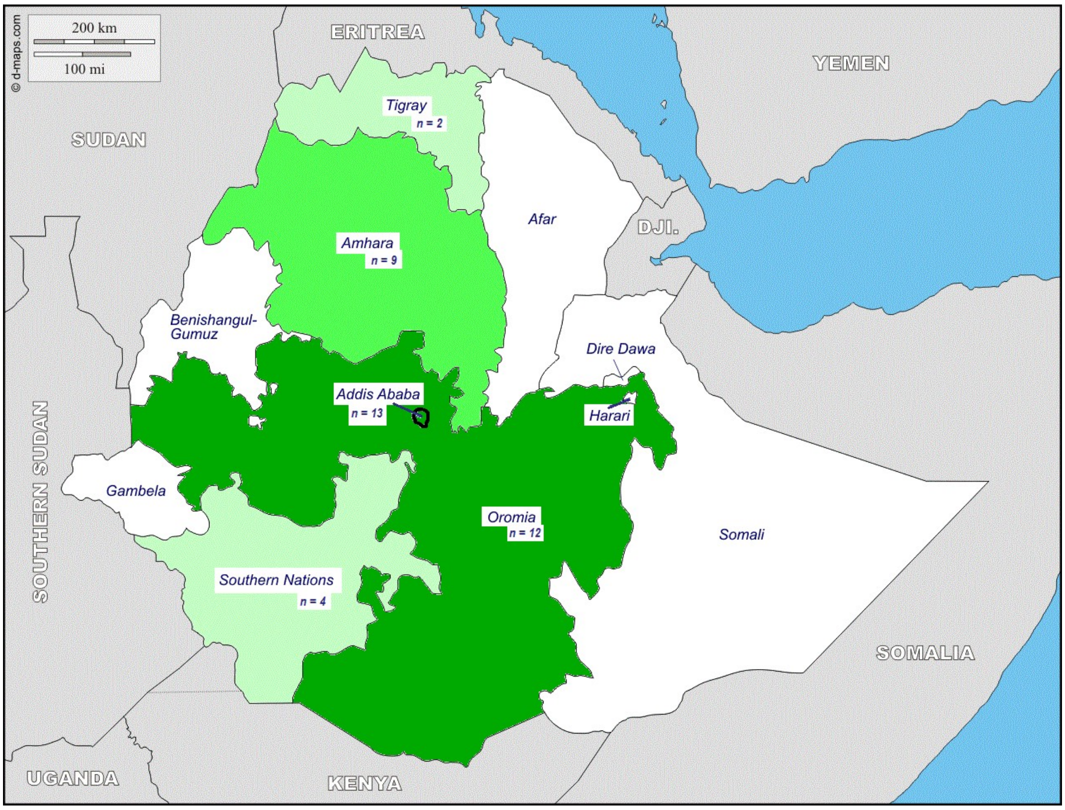


Figure 5 – Map of Ethiopia showing region of residence of patients participating in the study; map used from d-maps.com

4.3 Clinical presentation

4.3.1 First recognized sign

The first recognized sign is defined as those bodily changes which the patient herself thought to be the first which occurred and is connected with her disease. This has to be differentiated from a symptom, which is the bodily change which is detected by a health care professional. In some cases patients described more than one first recognized sign.

Quality of first recognized sign

Five different groups of signs (table4) are described by the patients:

- Unusual vaginal bleeding (constant, with discharge, intermenstrual, irregular)
- Pain (pelvic pain, during urination, headache, back pain)
- Heavy discharge (white discharge with or without smell)
- Vegetative (fatigue, loss of appetite)
- Others (swelling of one leg or belly)

A majority (27; 67.5%) of the patients complain about some kind of vaginal bleeding. *"I didn't know it was a disease, at first I assumed it was my period, but at the time I started seeing the blood discharge it was 15 years after I stopped seeing it, I was surprised to see it and I wondered whether I started seeing my period again, the discharge lasted a week then it stopped and then it started again after a year."(Patient 14)*

Twelve (30%) of the patients describe the bleeding as irregular, like the patient quoted above and five (12.5%) as constant. *"First there was bleeding. It started and then it was constantly there; day and night. It was not very strong. But it was always there." (Patient 36*) In nine (22.5%) cases the patients describe the bleeding as mixed with discharge. *"The first sign was a fluid kind of thing, it was a white sticky fluid, sometimes it was mixed with blood." (Patient 2)* One (2.5%) woman complained about bleeding after sexual intercourse and intermenstrual. *"Maybe 5 years ago I started seeing bleeding. It was after I was with a man and sometimes I had bleeding in between. That was in the beginning." (Patient 32)*

In nine (22.5%) cases the patients describe the bleeding as being mixed with a white discharge. Since most patients put the focus on the bleeding and also described this as such, I decided to assign this clinical presentation to the bleeding category. *"I think the first symptom was blood. One day it was there, like a period, but it lasted longer. And sometimes there was a white thing mixed with it." (Patient 39)*

Pain was complained by nine (22.5%) patients. Different kinds of pain were described: pelvic pain, pain during urination, headache and back pain. *"I was not very sick, but I was feeling some pain* *when I had my period, but the pain goes away after sometime, it used to come and go, I waited some time, I was confused with it." (Patient 3) "At first it felt like my back was in a fire, it was burning." (Patient 22)*

Six (15%) patients complained about heavy discharge. *"There was a fluid discharge… it was just a white fluid." (Patient 18)* Some patients described an unpleasant smell related to the discharge. *"I had this white thing in my underpants. It was a lot. I never had that before… That white thing sometimes was there and sometimes not. The smell was not good, so I did not like it." (Patient 30)*

Fatigue and loss of appetite I grouped together as vegetative symptoms; four (10%) of the patients described such. *"I used to get tired a lot, I was tired all the time, I wasn't able to move from place to place because it was hard for me to control my body and I didn't have the energy to do it." (Patient 20)*

In two (5%) cases patients describe a vaginal discomfort. *"I started to feel a different pain. It was in my private part. It was not really a pain. It was an uncomfortable feeling." (Patient 25)*

Increase of the girth and swelling of a leg were also described by two (5%) patients. These two clinical presentations I grouped as others. *"My stomach was very big, I used to look pregnant." (Patient 20)*

Table 4 - First described signs by patients with main symptoms in bold and subgroups in Italian

bledding	**27**	**67.50%**
irregular	*12*	*30.00%*
with discharge	*9*	*22.50%*
constant	*5*	*12.50%*
intermenstreuel	*1*	*2.50%*
postcoital	*1*	*2.50%*
Pain	**9**	**22.50%**
Back	*3*	*7.50%*
pelvic	*2*	*5.00%*
not disclosed	*2*	*5.00%*
Head	*1*	*2.50%*
during urination	*1*	*2.50%*
vaginal discharge	**6**	**15.00%**
vegetative	**4**	**10.00%**
vaginal discomfort	**2**	**5.00%**
others	**2**	**5.00%**

Number of initially recognized signs

Patients presented in average with 1.2 signs with a standard deviation of 0.5 and a median of 1. Number of first recognized signs ranges between 0 and 3.

While 1 (2.5%) patient was not aware of any signs she experienced, others could name one specific sign as being the first to occur and others had difficulties to differentiate which was the first.

"I didn't realize it was a disease, but there were fluids coming out, and I was tired all the time, and I had a headache. These were the symptoms." (Patient 14)

4.3.2 Other signs

As the disease develops most of the patients experience other signs in addition to their initial signs. An overview of those signs perceived in further process can be found in table 5.

12 (30%) of them did not experience any further signs. *"The bleeding was the only symptom; there was a constant bleeding, day and night." (Patient 17)*

On top of the already mentioned signs, patients mentioned the following further signs:

- Sleeping problems
- Paralyzed leg
- Urine abnormalities.

Pain is the main complaint which develops in the further process of the disease. Overall 21 (52.5%) of the patients describe some kind of pain which developed after their initially felt sign. In 9 (22.5%) cases women described a back pain and this was the most common type of pain described.

Development of pain during urination was mentioned by 4 (10%) patients. *"Then the pain got worse, now It is very hard for me to go to the toilet, because it is too painful to pee, I don't eat much I have lost my appetite, I have pain in my back." (Patient 15)* Development of headache is complained by 1 patient.

Further to the different kinds of pain mentioned as first complaint, a general pain is mentioned by 3 (7.5%) patients. *"And there was a pain all over my body." (Patient 23)*

Vegetative reactions are mentioned by 8 (20%) patients. On top of fatigue and loss of appetite, as already mentioned as first sign, sleeping problems were a further complaint. *"I don't sleep and it is hard for me to sit for a long time, I don't eat food, so they brought me here today to know what will happen to me now." (Patient 12)*

Unusual vaginal bleeding and heavy discharge were developed by 5 (12.5%) respectively 4 (10%) patients.

A vaginal discomfort is described by 3 (7.5%) women. *"Then I waited to understand what it was but it got worse, it was very much like `mech`." (Patient 13)* Mech is an Amharic word used for an itching feeling, normally caused by intense sunlight.

Sub-grouped in the category of Others are urine abnormalities, mentioned by 4 (10%) patients and swelling of a leg, mentioned by 1 (2.5%) patient. *"First it was blood then the blood was mixed with a white thing, and once I peed a green kind of thing, and some other time it was a yellow thing, there was some swelling, my whole body is in pain, I am tired all the time" (Patient 8)*

Table 5 - Further signs developing, bold main signs, Italian subgroups

Pain	**21**	**52.50%**
Back	*9*	*22.50%*
pelvic	*5*	*12.50%*
during urination	*4*	*10.00%*
not disclosed	*4*	*10.00%*
general	*3*	*7.50%*
head	*1*	*2.50%*
vegetative	**8**	**20.00%**
bleeding	**5**	**12.50%**
irregular	*2*	*5.00%*
with discharge	*2*	*5.00%*
constant	*1*	*2.50%*
others	**5**	**12.50%**
discharge	**4**	**10.00%**
vaginal discomfort	**3**	**7.50%**

4.3.3 Symptoms overall

Overall, unusual bleeding and some sort of pain are the major complaints (table 6). 29 (72.5 %) of the patients experienced unusual bleeding which was irregular, with discharge, constant, intermenstrual or after sexual intercourse. 26 (65%) of the patients complained about some sort of pain. The pain occurred in the pelvic, back, head, during urination or in general.

Heavy vaginal discharge, sometimes connected with an unpleasant smell, was described by 10 patients (25%). Similarly, 10 (25%) of the patients described vegetative signs like fatigue, loss of appetite or sleeping problems.

Vaginal discomfort was described by 5 (12.5%) of the patients and 6 (15%) complained about some other complaints.

An average of 2.2 signs with a standard deviation of 1.0 was experienced by the patients. The median of experienced signs were two. Experienced signs ranged between zero and five.

The following quote of a patient shows how a whole list of signs was experienced during the course of the disease. *"First it was blood then the blood was mixed with a white thing, and once I peed a green kind of thing, and some other time it was a yellow thing, there was some swelling, my whole body is in pain, I am tired all the time, this are the symptoms." (Patient 8)*

Table 6 - Signs experienced overall, main categories in bold, subcategories in Italian

Bledding	**29**	**72.50%**
Irregular	*13*	*32.50%*
with discharge	*11*	*27.50%*
constant	*6*	*15.00%*
intermenstreuel	*1*	*2.50%*
postcoital	*1*	*2.50%*
Pain	**26**	**65.00%**
Pelvic	*7*	*17.50%*
Back	*7*	*17.50%*
not disclosed	*7*	*17.50%*
during urination	*5*	*12.50%*
General	*3*	*15.00%*
Head	*2*	*5.00%*
Vaginal discharge	**10**	**25.00%**
Vegetative	**10**	**25.00%**
Others	**6**	**15.00%**
Vaginal discomfort	**5**	**12.50%**

4.3.4 Interpretation of signs

Some patients interpreted their bodily changes as being normal or not serious. *"Nothing, I waited. I thought it will go away. It did not hurt, so I thought it cannot be harmful."(Patient 28)* Others realized that something was wrong, but they did not have any specific interpretation for their signs. *"I saw that something was wrong. I knew that that should not be there. I knew I should go to the doctor." (Patient 36)*

8 (20%) of the patients assumed that their period had returned. *"I didn't know it was a disease, at first I assumed it was my period, but at the time I started seeing the blood discharge it was 15 years after I stopped seeing it, I was surprised to see it and I wondered whether I started seeing my period again." (Patient 14)* Not all of the patients which interpreted their signs as their period already passed menopause. *"My period didn't stop when the sickness started, that's why I mistook it for a period, it looked like a period, but when it wasn't stopping after some time I got worried then the pain started." (Patient 16)*

Another interpretation given was a possible pregnancy. This was made by 1 (2.5%) woman. *"There was bleeding, it lasted for seven months, I assumed it was a pregnancy so I started using medicine, so* *when I stop the pill the blood returns when I take the pill the bleeding stops, then I decided to go to a hospital and get it checked out." (Patient 17)*

In 1 (2.5%) case a woman related her bleeding to an external event. *"My 28 year old son died and I was crying and when I got up I was bleeding, at that time I had stopped seeing my period for twelve years, I thought it occurred to me because I was shocked by his death." (Patient 8)*

4.4 Patient Navigation System

4.4.1 Visit health stations

The health system in Ethiopia consists of three tiers (figure 6): the primary level (PL) consists of health units, health centres and primary hospitals; the secondary level (SL) consists of general hospitals and the tertiary level (TL) consists of specialized hospitals. Next to it, there is the private sector (PS) which consists of private clinics and private hospitals.

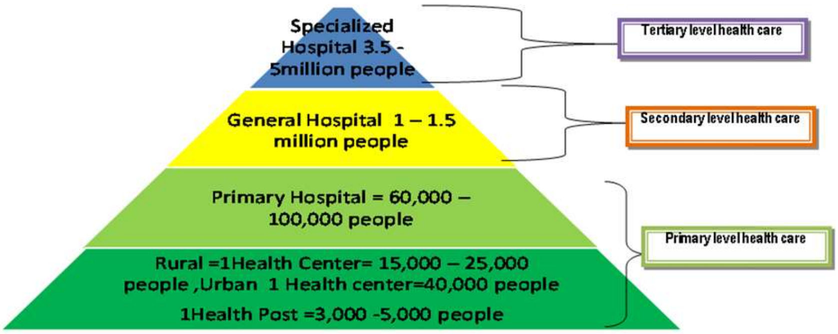


Figure 6 – Ethiopian health tire system from http://www.aho.afro.who.int/profiles_information/index.php/Ethiopia:Service_delivery_-_The_Health_System

Visits to the health system are categorized in these four areas and shown in table 7 for each patient. Each visit is counted, but revisits due to collection of results or for diagnostics are not counted.

Table 7 – visits to health nodes of each patient; PL=primary level, SL= secondary level, TL= tertiary level, PS= private sector; blue= suggested point of diagnosis

Patient	1st visit	2nd visit	3rd visit	4th visit	5th visit	6th visit
1	PL	PS	**SL**	TL		
2	PL	**PS**	SL	TL		
3	PL	**SL**	TL			
4	PL	PL	**SL**	TL		
5	PS	PS	PL	**SL**	TL	
6	PS	**TL**				
7	PL	PS	**SL**	TL		
8	PL	SL	**PS**	SL	TL	
9	PL	SL	TL			
10	PL	**SL**	TL			
11	PL	**SL**	TL			

12	SL	SL	TL			
13	PL	PS	PS	**SL**	TL	
14	SL	TL				
15	PL	SL	SL	TL		
16	**PL**	TL				
17	PS	**SL**	TL			
18	PL	TL	PS	TL		
19	PL	**PS**	SL	TL		
20	PL	SL	TL	SL	TL	
21	PL	PL	**PS**	PL	TL	
22	PL	SL	TL			
23	PL	TL				
24	PL	PL	PL	PS	**SL**	TL
25	PL	**SL**	TL			
26	PL	PL	PL	SL	SL	**TL**
27	**PS**	TL				
28	SL	TL				
29	PL	PL	SL	PS	SL	TL
30	PL	PL	**SL**	TL		
31	PL	PS	PS	**TL**		
32	PL	PL	PL	**SL**	TL	
33	PL	PL	PL	**SL**	TL	
34	PL	PL	SL	TL		
35	PL	**SL**	TL			
36	**PS**	TL				
37	PL	PS	**SL**	TL		
38	PS	**PS**	TL			
39	PL	PL	SL	**SL**	TL	
40	PS	PL	**SL**	TL		

First access to health level

In 30 (75%) cases women accessed the health system at the primary level. Most of them visited the closest health centre when they decided that they have to see a doctor. 3 (7.5%) of the patients went straight to a local hospital, thus they went straight to the secondary level. 7 (17.5%) of them went first to a private hospital or clinic.

Overall visits

Patients had an average of 3.8 visits to health station (HS) with a standard deviation of 1.2. Table 8 shows how many patients visited how often a HS. The median visits were 4 visits. Minimum visits to HS were 2 and maximum visits were 6.

Table 8 - Number of patients of visits to HS

visits to HS	no of patients	percentage

2	7	17.50%
3	10	25.00%
4	12	30.00%
5	8	20.00%
6	3	7.50%

"First I went to a private clinic, I went to 'Tekle Haymanot' hospital, then they saw the fluid discharge and they told me my womb is no longer good, and they wrote a refer to Tikur Anbessa hospital then I came here" (Patient 6) This is a common example of one of the patients who had only two visits. From those 7 (17.5%) patients, 3 of them first went to the private sector, 2 to the secondary level and 2 to the primary level.

Those 3 (7.5%) women who visited six different HS followed different paths to TAH:
PL – PL – PL – PS – **SL** – TL *(Patient 24)*;
PL – PL – PL – SL – SL – **TL** *(Patient 26)*;
PL – PL – SL – PS – SL – TL *(Patient 29)*.
"I decided that I have to go to a doctor and so I went to the next health center. There I got some medicine. It were white pills. I don't know why I had to take them. It did not help. Nothing changed. So I returned and the doctor said that I have to go to a hospital. So I went there and again I got some medicine. But that also did not help. I was very upset and I did not understand… So we went to a private clinic. Again they gave me medicine and said I have to do some tests. But they could not do them, so I should return to the other hospital. But they gave me a letter and told the doctors what to do. So I returned there and then they said that I have to go to AA to a big hospital". (Patient 29) This example shows that reason for increased number of visits can be due to misdiagnosis. This and other reasons will be discussed more deeply later on.

Even women with fewer visits tell a similar story. *"I went to two different health centers and they tried a number of things but they didn't help, then I went to a private clinic with my son then they examined me and they told me I need to go to a big hospital as soon as possible, so they wrote a letter to the health center asking them to write a referral letter to a hospital, then the health center wrote the letter to TAH." (Patient 21)* Overall 8 (20%) women had five visits to different HS like this woman.

12 (30%) women visited 4 different health stations and 10 (25%) women visited 3 HS.

Of the 10 women who visited 3 different HS, 7 (17.5%) of these cases visited the health system exactly as planned by the government: PL – SL –TL. *"After going to the health centre I went to St. Paulos Hospital then they referred me to Black Lion." (Patient 11)*

Referral system

The Ethiopian health system is set up as a structure where patients should be referred between the different levels, from the bottom to the top. As mentioned above, patients with serious diseases should access the health system at the primary level and then be referred to the secondary level and then finally to the third level. Diseases should be treated on the level where the doctors have the possibility of treating them.

In this study one example can be found for downward referral. *"At Yekatit hospital they operated on me and took out a gland, after that they sent me to Tikur Ambesa for further testing because I was still not healed, so I came here and they tested me for different things and they gave me the result, I took the result back to Yekatit Hospital, then they referred me back here for another treatment." (Patient 20)*

More examples can be found for revisits on the same level. 14 (35%) patients describe multiple visits on primary or secondary level or to the private sector. *"It was the health center close by… I returned to the health center… So we went to the hospital. There they did a lot of things. For 3 days I had to come and go to the hospital. They needed blood and urine and also looked at me. In the end they said it might be cancer and that I have to go to a bigger hospital. Then I went to the hospital in Jimma… But in the end they said that they can`t help me and that I have to go to TAH." (Patient 39)* This patient visited the same health centre twice, before she visited two different hospitals on the secondary level. While her revisited to the health centre was due to erroneous treatment, she had the two visits on the secondary level due to wrong referral. Even though the possibility of cancer was diagnosed in the first hospital, they referred her to another hospital which could not treat her.

Role of private sector in Ethiopian health system

Visits of health stations in the private sector were done by 19 (47.5%) of the patients. 4 (10%) of them visited the private sector twice.

Comparing the group of patients who visited a private clinic and those who did not visit a clinic from the private sector, it can be found that the average visits to health stations of those who had visited a private clinic were 4 (19 patients) and those who did not 3.5 (21 patients). But with a standard deviation of 1.2 in both cases no generalized conclusion can be drawn from this comparison.

Point of diagnosis

In some cases patients could name the point where the diagnosis of cancer was made or suggested. This point is marked in blue in table 7. Overall 28 (70%) of the patients mentioned this point. In 22 (55%) cases the diagnosis was made one step before TAH. Thus, besides the one example given in the chapter above, as soon as a doctor assumed a possible case of cervical cancer the patient was referred to the right hospital. In 18 (45%) of these cases the diagnosis was made in a hospital on the secondary level, in 3 (7.5%) cases it was made in a private clinic or hospital and in 1 (2.5%) case it was made in the primary level. *"It was Gandhi hospital in AA. There they also examined me and then they said that it is cancer and that it is too late for operation so I have to go to TAH." (Patient 37)*

In 3 cases the right diagnosis was made in TAH. So, patients were referred to the right hospital without anyone assuming that they might have cancer or patients could not recall that a suggested diagnosis was made along the pathway to treatment.

In 4 (10%) cases cancer was diagnosed two steps before the patient arrived in TAH. *"After seeing this I went to 'Bahir Dar' and they examined me using ultrasound then they understood it was cancer, then they referred me to 'Gandi' hospital, at 'Gandi' they took a small sample from the infected area and they sent me to 'TAH'. People in 'Bahir Dar' hospital sent me to 'Gandi' hospital because they assume I will get surgery but the people in 'Gandi' assumed that they couldn't perform surgery because it can only be treated by radiotherapy." (Patient 2)* In this case the doctors assumed that treatment could be possible in another hospital than TAH. In another case, a patient was first send to a public hospital with the request to refer her to TAH.

Misdiagnosis

Misdiagnosis was common among the women interviewed. A common misdiagnosis was some kind of infection. 7 (17.5%) of the patients were diagnosed with a STD. *"They told me it was a STD and they gave me a medicine for it, so I believed them and I took the medicine but it didn't stop the bleeding." (Patient 2)* In 2 (5%) cases the patients were diagnosed with a urinary tract infection (UTI) and in 2 (5%) other cases patients were diagnosed with tuberculosis (TBC). 1 (2.5%) patient got antibiotics but she did not remember which kind of infection was supposed to be treated.

In 1 (2.5%) case a patient was treated three times against infections. *"They said that I have an infection. This is because I sleep with different men and I should stop that…They gave me antibiotics and advised me to use condoms… So I returned to the clinic. They said that as long as I sleep with men it will return and they gave me antibiotics again. I took them…They said that I`m in a terrible state and they send me to hospital. They said I have a serious infection and that I need special antibiotics." (Patient 32)*

In 4 (10%) cases patients were treated against period irregularities or return of their period. *"When I went to the health center, they gave me a pill assuming that there was a mix-up in my menstruation schedule, but the pill didn't help it only made it worse" (Patient 19)*

Pain medication was another treatment applied. In 3 (7.5%) cases the woman got a prescription for pain medication. *"So I went to a private clinic and said that I have a pain in the back. And then they described me pain medication. That helped for some time."(Patient 39)* In this example the patient did not mention all her clinical signs, since she interpreted the bleeding as her period. *"He said it is not serious and it is just because of my other disease. I got some pain medication." (Patient 25)* This patient also got pain medication due to her preexisting disease and does not think about the possibility of another disease existing.

In 2 (5%) cases, women received some kind of medicine, but could not define this any more precisely. It is unlikely that they received some kind of appropriate cancer therapy.

Some women going to hospital or health centres presenting their signs were told that they have nothing. *"Then I went to the hospital, they told me I have nothing, it was for three month that they said I have nothing but the blood didn't stop, so I paid 5000 birr and got treated in a private hospital, they took sample from my womb and they said it is clean, there is nothing wrong with my womb." (Patient 7)* In this case the woman went to two different HS and in both cases she was told that everything is alright. She presented with vaginal bleeding, a common gynecological symptoms. In the first health station they did not do anything, but send her home. In the second health station they did some kind of diagnostic test, but this test did not show a result.

In another case it becomes obvious that health workers were not informed about possible clinical presentation of cervical cancer. *"I started to feel some pain, so I went to Ethiopia family planning, and I paid 95 birr, then I went to the examining room, and I told them I have some discharge, then she asked me to lay down, and she saw that the discharge was bloody, and she told me "pre cancer can't come like this, a mixture of blood and other fluids" and she advised me to ask a refund of my money and go back, so I did that, I went home, then the pain continued for some time, after some time the blood discharge stooped so I went back to Ethiopian family planning, and she examined me again, she was wearing a glove and she told me that there is blood inside, and they gave the money back and she sent me home." (Patient 5)*

Misdiagnosis seems to be an important factor influencing the patients` pathway to treatment. Misdiagnosis leads to a delayed diagnosis, referral problems and increases the number of visits to the health stations.

4.5 Influence traditional medicine

Traditional medicine still plays an important role in the Ethiopian health system. It fills a gap where the public health system cannot provide sufficient services. It has a long tradition and it serves a wide range of services.

Women, participating in this study, talked about two different kind of traditional medicine: traditional healers which provide herbal medicine and holy water which is used by Orthodox Church.

16 (40%) of the patients used one of the two methods, four (10%) went to traditional healers and twelve (30%) used holy water.

The benefit of traditional medicine was valued in different ways. *“Yes, we used it but it just made it worse, it was a traditional herb which didn’t help, she took it once, twice or three times, it was three times. (Patient 9)”* While this patient sees the influence of traditional medicine as negative, another patient feels more comfortable and feels a positive benefit from using it. *“I went to a healer. He does not live far and he is very famous. We trust him. Everyone goes there. He gave me some medicine. It was a cream and he said that I have to apply it…I did that for a month. But it did not help. But I thought if this does not help than it cannot be serious.” (Patient 30)*

In all 4 cases where patients used traditional medicine they went there, before they visited the health system. In 3 cases they got traditional medicine and used it for some time. Only in 1 case a patient went there and was told that she has to go to the hospital. *“I haven’t used it, but I went to consult them and they told me to go to hospital because they have no ideas what to do with it.” (Patient 15)*

Similarly, patients using holy water used that for some time before they relied on the health system. *“First I went to church for holy water. I went to those in Entoto area (outside of AA). There I prayed and I got holy water. I thought that should help. But apart from that I did not do anything.” (Patient 28)* Other patients use holy water parallel to their visits to the health stations. *“I was using holy water as another aid, I also consulted with the doctors but I used to go to the church for holy water.” (Patient 6)* In another case it becomes obvious that they use holy water because they are disappointed in the school medicine. *“She uses the holy water because we are not getting anything from the hospital.” (Patient 8)*

4.6 Timing & delay

4.6.1 Pathway to treatment

In order to describe delay I applied the pathway of treatment model which derived from the Andersen model of delay (Walter et al., 2012). Delay is separated into 4 intervals: appraisal, help-seeking, diagnostic and pre-treatment interval. These intervals are determined by clearly defined events (figure 7).

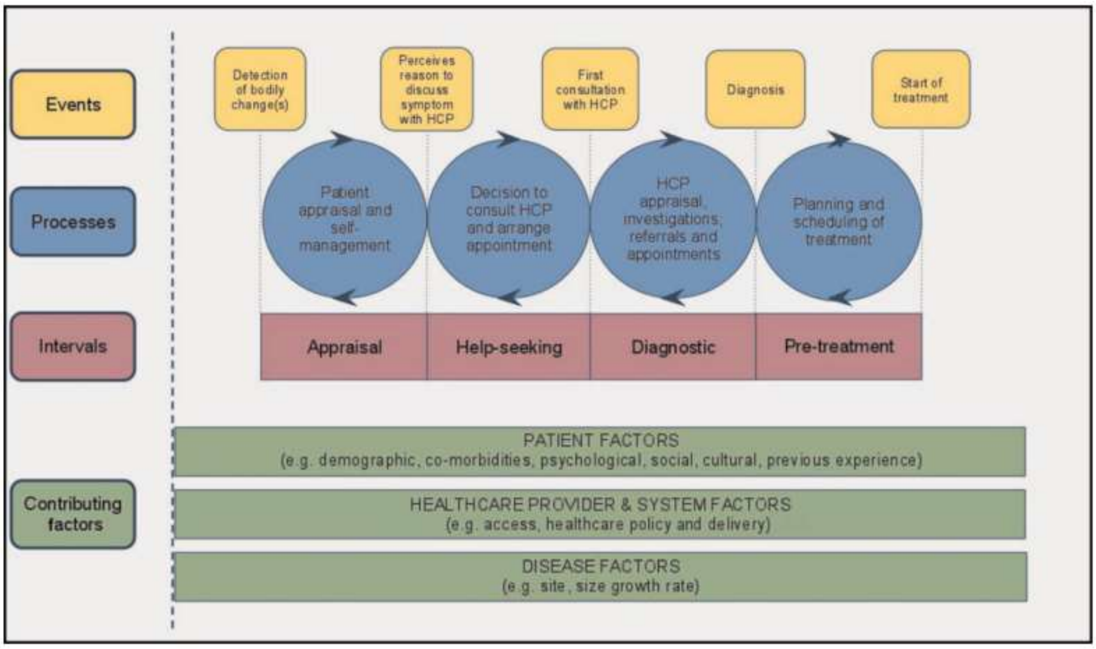


Figure 7 – Model of pathway to treatment by Walter et al.

The appraisal interval starts with the detection of bodily changes and ends with the decision to discuss this with a health consultant. In this interval the patient has to appraise their bodily changes as being serious and not normal. Also, a decision of which kind of reaction is necessary, has to be made: can they be self treated, is medication needed, could traditional medicine be helpful.

Next, in the help-seeking interval, the patient arranges an appointment with a health care provider and this interval ends with the first consultation. In this interval it is not only the patient who plays a part but also the health institution. Appointment could be set on the next day or within the next weeks, depending on the seriousness presented. In the case of Ethiopia the first consultancy with a health provider is not due to an appointment, because patients go directly to the health centre. But factors like long travelling time, travelling costs and not presence of the health care provider could play a role in the length of the interval passing.

Afterwards, the diagnostic interval starts and this ends with the diagnosis. In this time, the health care providers are mainly responsible for the amount of time passing. They have to interpret the symptoms in the right way, starting the referral process and diagnostic tests have to be done. However, as mentioned by Walter, a reappraisal interval can take place in between, with the patient hesitating to proceed with the path or doubting that they are on the appropriate path (Walter et al., 2012).

With the diagnosis made, the pre-treatment interval starts. In this interval the treatment is planned and scheduled and the interval ends with the beginning of the treatment. Since patients had difficulties to tell the exact point of diagnosis, I decided that the pre-treatment interval is the time passed in TAH until the treatment starts.

Furthermore, contributing factors influence the whole pathway of treatment. These consist of patient factors, health provider and system factors and disease factors. Patients make different decisions depending on their previous experience, their culture, their religion, their co-morbidities, etc. In the same way, each country, state and city has a different infrastructure and different education programs. Also, each health provider is an individual and is influenced in his decision making by the same factors which influence patients. Furthermore, each disease presents in a different way and is therefore interpreted in different ways. While some cancers present with typical cancer signs, like breast cancer with a lump, other cancer like colon cancer are more unspecific.

4.6.2 Time intervals passed

Time intervals which passed were extracted from the interviews. Not all patients made remarks on each single interval, as described by Walter et al. However, those intervals which were mentioned by the patients gave some ideas about which time length passed. Figure 8 shows those intervals which were mentioned by the patients ordered by length of all intervals mentioned.

Appraisal interval

30 (75%) of the patients could name a time which passed between recognition of first symptom and the decision to visit a health care provider. The average time which passed in the appraisal interval was 10 month with a standard deviation of 11. The median appraisal interval was 6 month, ranging between 1 and 48 months.

Help-seeking interval

Only 2 (5%) patients mentioned that time passed between the decision to visit a health care provider and the actual visit. In 1 case 12 months passed, in the other case 4.

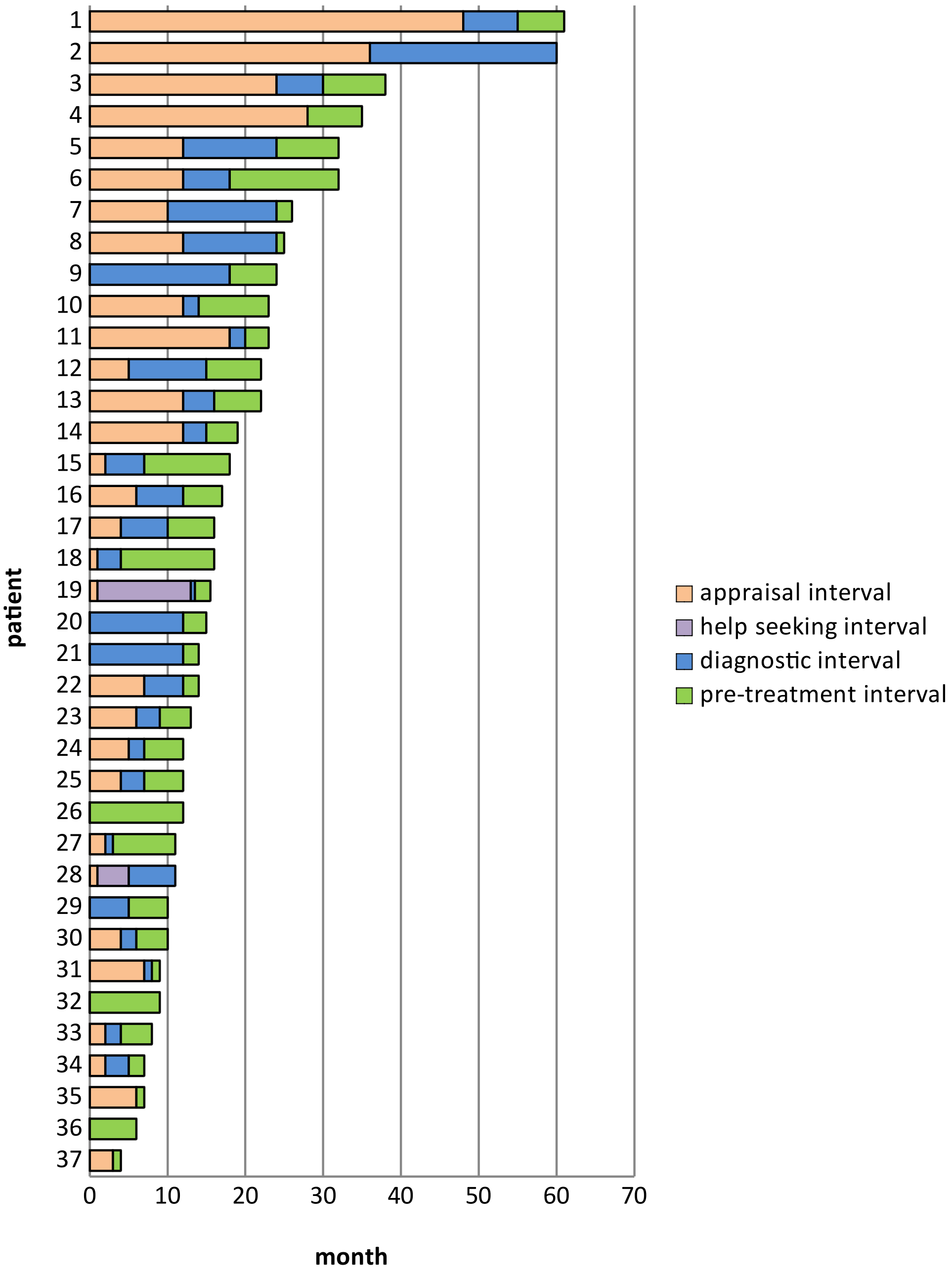


Figure 8 – Patient delay separated into appraisal, help seeking, diagnostic and pre-treatment interval; sorted by maximum length described; not all intervals described by each patients.

Diagnostic interval

Overall, 31 (77.5%) of the patients named a diagnostic interval. An average of 7 months passed with a standard deviation of 5. The median value was 5 month. The interval ranged between 0.5 and 24 months.

Pre-treatment interval

Nearly all patients could name the time which passed inside TAH waiting for treatment, 35 from 40 patients. Patients passed an average of 6 months inside TAH until treatment started. The standard deviation was 3. The median time was 5 months. The time ranged between 1 and 14 months.

Minimum total delay as described by patients

A majority of patients could not name interval length for all above described intervals. In order to get an idea about the time which might have passed, I added those intervals which were named by the patients and called this the minimum total delay. Since most patients were at least missing one interval, the actual time passed between first recognized sign and treatment has to be assumed to be longer.

The average minimum total delay, the time which passes between recognition of the first symptom and start of treatment, was 19 months with a standard deviation of 13, ranging between 4 and 61 months.

Another way to approach total delay could be to sum up average values of each individual interval. This would lead to a total delay of 31 months.

4.6.3 Reasons for delay

In this chapter, reasons for delay will be discussed which lead to a prolonged time interval. These reasons are discussed for each single interval and then displayed in figure 9.

Appraisal interval

As mentioned above in the chapter `interpretation of symptoms´ patients interpreted their symptoms in different ways. Some of the patients found natural reasons for their clinical presentation, for example, recurring of their period or a pregnancy. Others understand that something was different, but did not interpret it as harmful. In both cases, patients interpreted their bodily changes in a way which did not make it necessary for them to seek help. *“I stayed at home for one year thinking it will go away” (Patient 4)*

Furthermore, patients felt ashamed for their bodily changes and did not want to talk to anyone. *“I am a very old women how can I tell anyone I am seeing blood at this late age” (Patient 15)* This led to a further delay since the patient could not open up to anyone and did not allow herself to fully interpret her bodily changes.

Another reason which led to delay was the use of alternative medicine. *“Before I went to the Health center I went to a traditional healer. He gave me some medicine. I took that for a month. But it did not help.” (Patient 24)*

Help seeking interval

After patients realized that they have to take their symptoms seriously, most patients rushed immediately into hospital. But in some cases time passed between making the decision that they needed help and the moment when they arrived in hospital.

"Even when I saw the first discharge I went to hospital but the doctor was not there for three days so I wanted to go the next week but the discharge stopped then I decided not to go." (Patient 14) This is a common example for provider delay. The patient has decided that she had to go to the health center, but the doctor simply was not there. After three visits she gave up.

In the chapter `contributing factors´ some reasons will be discussed which look closer at the issue of problems accessing health facilities. This is a problem which can lead to delay in both help-seeking and diagnostic interval.

One patient explained why other people did not seek help, even though they realized that their symptoms might be harmful. *"The first thing is people are afraid to go and get tested before anything happens to them, and no one checks it before time, when I checked it my friends were very surprised because they never thought I will check because no one does, but the good thing is since it is not in a worse state it is easier for me to get treated, but if it was in a later state it would have been hard for me to recover quickly, so that's why I went there early, but most people see cancer as a very bad thing and they never go and check their health when they see some symptoms…. They see cancer as a killer disease." (Patient 3)* This explanation gives a general impression about what people think about serious diseases. Fear of getting a terrible diagnosis and also the impression that no one can help them was a further barrier to access health system.

Diagnostic interval

Delay in the diagnostic interval was mainly due to two reasons: misdiagnosis and problems in the referral system. Both reasons are discussed in depth in two separate chapters above. Both reasons are related to each other. If the healthcare provider thinks that some simple disease causes the bodily changes they do not see a necessity in referring patients further and instead treat them with what they think is the appropriate treatment.

Revisits are further delayed by different reasons accessing treatment, like transport system, money issues or time problems and will be discussed in the chapter `contributing factors´.

Pre-treatment interval

The long waiting time in TAH was the main reason for delay in the pre-treatment interval. *"Then I returned for a checkup then they told me I need radiotherapy then I waited for a year then I got my* *turn and I received 32 radiotherapies." (Patient 18)* This long waiting time was due to the fact that radiotherapy facilities are scarce in Ethiopia. Since TAH is the only hospital in Ethiopia which offers radiotherapy they have to treat all the patients, which need such a therapy. Furthermore, the facilities in TAH are already old and sometimes did not work properly and had to be repaired. *"I started last week. Two days the machine did not work but overall it is good." (Patient 28)*

Another problem arose for patients since they were forced to stay in Addis Ababa as long as they were waiting for radiotherapy and also during radiotherapy. This stay was related with a lot of costs and also the absence at home and at work. *"I don't have much money. I run a small shop, and no one was working there, so I first had to return and look after the shop. I returned and worked in my shop. I talked to my friend and she said I have to get treatment, but I only saw the cost. I don't know how to afford to stay in AA." (Patient 26)*

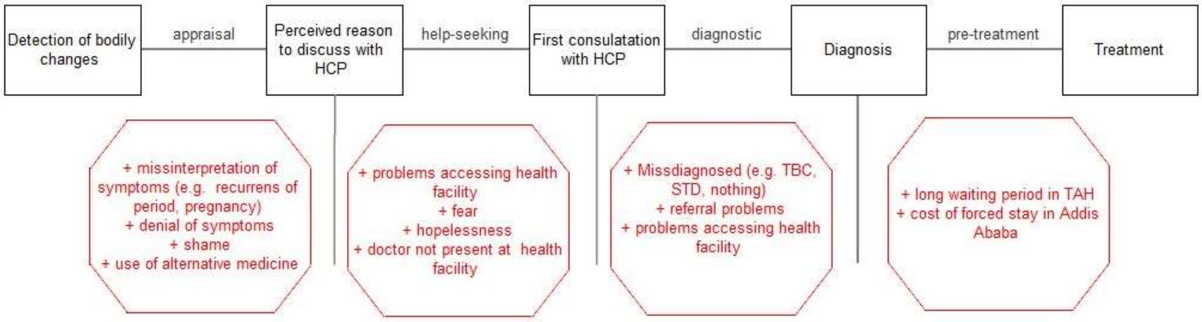


Figure 9 – Reasons for delay mentioned by the patients

4.6.4 Triggers for action

While I discussed reasons which caused delay in the help seeking process, I also want to look at reasons which motivated patients to seek help and to stay within the help seeking process. These triggers are displayed in figure 10 at the end of this chapter.

Triggers for action could not specifically be related with a fixed event. Thus, it was difficult to sort them exactly to a certain time interval. Therefore, I decided to assign them together to the appraisal and help-seeking interval, the timeframe before people accessed the health system, and to the diagnostic and pre-treatment interval, where the patients were already inside the health system.

Triggers for action in appraisal and help seeking interval

Even though patients realized their symptoms they did not always see the seriousness behind it. Something had to happen in order for them to realize the seriousness, so these are reasons why they ended the appraisal interval. As it will be seen below, often this led to immediate action and therefore, also ended the help seeking interval.

The main trigger for action during this time was involvement by others. The involvement was either by chance, visitors saw the bad condition of the patient or the patient revealed her symptoms to others.

"Then on September I was at home preparing food and other things for the holyday when I collapsed, then the whole family was in shock, when they asked I told them 'I have been seeing blood since April' and my daughter was angry at me because I didn't tell them sooner, then I replied 'I am a very old women how can I tell anyone I am seeing blood at this late age', then they rushed me to the hospital" (Patient 15) In this case close family members were the one who realize the seriousness of the symptoms and brought the woman into hospital.

Similarly, one more woman spoke to her family about her symptoms, but she also talked to other people and they were the one who made her realize that she has to go to the health center. *"I spoke with my daughter; I told her everything, my son when I told him I was seeing blood. He kind of assumed that he will get younger brother soon, but everyone laughed at him, but our neighbors told me it might be a sickness, so I went to the health center right away, …, so it was good that my neighbors told me to go to health center. If I hadn't gone there, I wouldn't have been here, and it stopped me from searching for other medicine like a traditional healer." (Patient 2)* Here, the neighbors did not only make her realize that she needed help, but also that she has to access the public health system and not use alternative medicine.

These two examples showed, which benefits involvements by others can bring. First of all, the patients got support and encouragement by others. They felt that people stand behind them and also that people would support them on the way to and at the hospital. They did not have to be alone anymore and have people on their side who support them. On the other hand, others can bring a new interpretation for the bodily changes. Also, more knowledge can be shared. *"One day my daughter came. She told me that she had heard from a friend that her mother has something similar and that she got treated in TAH. She survived it and that I have to get treatment because otherwise I would die. That was when I decided to go. So I went with a bus all the way. Luckily my daughter came with me." (Patient 29*) Thus, the more people who got involved, the more knowledge can be shared.

But, further knowledge and new information could be gained not only from other people, but also from other sources. *"Around that time [when I was seeing blood discharge] I was watching television and the doctor said blood discharge is one of the symptoms of cancer, so I rushed into 'Jimma' Hospital." (Patient 14)* This example underlined the successful use of media in sharing information.

A change in symptom or worsening of symptom was also mentioned as a trigger for action. *"But then one day I also had blood mixed with the white. I knew that that should not be there. Blood should not* *appear there. That was when I told my husband about it." (Patient 30)* The change of the initial symptom made this patient realize that her bodily changes might me more serious than she had thought in the beginning. With this realization, she decided that she needed help and involved her husband. Thus, the worsening of symptom changed the interpretation and also changed the behavior of the patient. *"I am not sure but it was a while back, the pain was getting worse so I decided to go to a health center and they saw my situation and they referred me to Yekatit Hospital." (Patient 20)*

Triggers for action in diagnostic and pre treatment interval

During the time of attempting to gain treatment, barriers arose for the patients. They were faced by new situations which they might be afraid of. The following patient described one of her struggles.

"They asked me to sign in a paper before I take the radiotherapy, I hesitated and told my children that I would not sign and I would prefer to use holy water, but they encouraged me and told me it would not hurt, people have told me before hand that radiotherapy would hurt my liver and other part of my body, so I decided to first observe what they do then to decide, …, so first I wasn't comfortable to try it and it is upsetting when you have children and when you are faced with this kind of disease, so I was in a dilemma but my children encouraged me, so I decided to try it for one time and then I will decide, so I came here and I was sitting in the waiting area and I asked the girl sitting next to me about it and she told me that it doesn't hurt and it improves the health status, so at that point I decided to go all the way, but people tend to discourage you, they tell you the problems" (Patient 6)

Three different kinds of triggers for action could be found in this paragraph: first, encouragement of her children, second, the worry for her children and third, the woman in radiotherapy unit who helped her to conquer her fear. Just as described earlier on, other people work as motivational factors to stay inside the health system.

From the health professionals' side not many motivational factors could be found. Patients had little knowledge regarding their disease and their therapy. But some of the patients trusted enough into their authority so that they followed the doctor's advice. *"No they did not. But I also did not ask. I do not understand these things. They tell me what to do and where to go and I follow that." (Patient 29)*

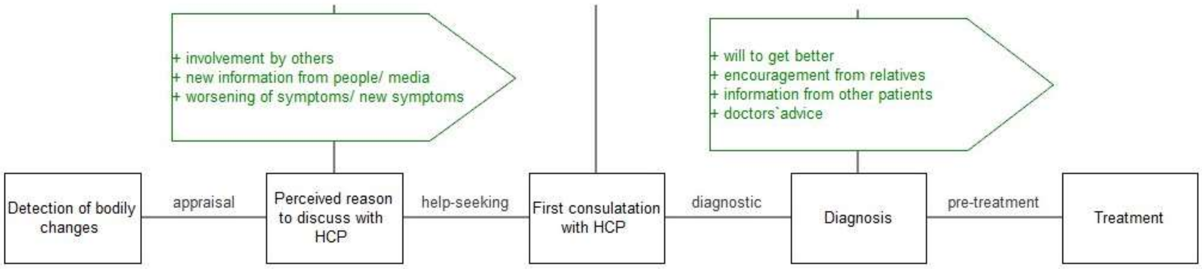


Figure 10 – Triggers for action as named by patients

4.6.5 Contributing factors

Patient factors

Patient factors consist of demographic background, co-morbidities, psychological, social and cultural factors, and previous knowledge. These points were not mentioned directly by patients, but looking closer at the interviews some hints could be found how patients` behavior is influenced by certain factors. Mainly, medical literacy of patients and their relatives seemed to have an influence. *"So I called my friend. She is a doctor from Gondar and she advised me to talk on the same day to the doctor." (Patient 36)* This patient waited a long time until she asked her friend for advice. This friend could tell her exactly which doctor she should visit and also explained her friend that she should immediately seek help.

Another aspect was social stability. This consisted of a strong family background and financial security. Families supported the patient along the whole pathway of treatment, encouraging them to go to health facilities, accompanying them on their visits and caring for them at home and in the hospital. *"They [my children] support me. I told my children about it. I have 4. 1 lives abroad so he is not here. But he sends money. The other ones all live in AA so I can stay with them and they support me a lot. They are a great help." (Patient 31)* This point will also be discussed in depth in the chapter `support by community".

Many costs arose for travelling and forced stay in AA. *"I paid a lot of money for the examination then I found out it was cancer, when I came here I had 9000 birr, so by now we have nothing we have spent all the money on food and for a place to stay." (Patient 13)* Coming from all over Ethiopia and having only the chance of getting treatment in AA forced patients to stay in AA for some time. Some of them had the chance of living with relatives; others were forced to rent a room. On top of that were the costs for transportation services. *"And me coming from outside of the city transport and housing are other problems." (Patient 1)* Transportation costs did not only arise coming to AA, but also beforehand when people wanted to go to the next health post or local hospital. *"I didn´t go to hospital for some time, I didn't have any money." (Patient 8)*

In addition to the fact that people had to spend a lot of money, they also could not work in between treatments. *"I faced problems in my work, I am a teacher and it was hard to get a time off from work to follow my treatment, they used to cut my salary because I was not present most of the time, but now they understand and help me, but in the beginning it was hard." (Patient 17)*

Healthcare provider & system factors

These factors describe the influence the health system has on the pathway to treatment. They describe access, healthcare policy and delivery.

Access to the health system was difficult for patients due to financial and transportation problems. Every visit to the health system was related with expenses. First of all, patients had to pay for diagnosis and treatment itself. Since health insurance was rare in Ethiopia every visit to a HS had to be paid for and further expenses arose for medication and medical devices. There existed the possibility of obtaining free health services, when a letter from the Kebale could be provided. Inside TAH we found that three groups of patients exists: free users, regular group and private group. Depending on which group patients belonged to, the waiting period was longer or shorter. *"After that money was one of the issues, they asked me if I wanted to be in the regular group or in the private group, so I chose to be in the regular group because I didn't have any money. So I waited for 6 months." (Patient 2)*

Even though, Ethiopia had done a lot in recent years to increase health care delivery for their citizens, patients often still had to travel long distances to reach the closest health center or local hospital.

Another aspect arising is the problem of unskilled health care workers. Since interviews were done with patients and not with health care workers, the information gathered was due to indirect explanation by patients. However, hints were given that health care workers were not always knowledgeable of cervical cancer.

As discussed above misdiagnosis was common. This showed that health care workers were not aware of possible signs and symptoms of cervical cancer. *"I went to Ethiopia family planning, and I paid 95 birr, then I went to the examining room, and I told them I have some discharge, then she asked me to lay down, and she saw that the discharge was bloody, and she told me "pre-cancer can't come like this, a mixture of blood and other fluids" (Patient 5)* Considering that this woman was already in menopause, a bloody discharge should be interpreted as a serious gynecological symptom. But the health care workers just sent her home.

Furthermore, after a suggested diagnosis of cervical cancer, referral sometimes did not go as planned. Patients were send to hospitals were they could not get treated. This showed that health care workers were not aware of appropriate treatment possibilities for cervical cancer in Ethiopia.

Problems also occurred due to shortage. Medicine could not always be delivered by the pharmacy. *"Getting medication is very hard sometimes when there is no medication in black lion I go to other pharmacies to buy it." (Patient 12)* Not only medication was not always available, but also the radiotherapy machine did not always work. *"Today the machine is not working but other than this I haven't seen any problem." (Patient 6)*

Disease factors

Cervical cancer becomes symptomatic in an advanced stage. Therefore, patients do not realize in early stages that they are sick. As was discussed early in this study, common first signs recognized by the patients were unusual vaginal bleeding and some sort of pain. These signs were often not taken serious by patients and health care providers alike and lead to misdiagnosis by health care providers and misinterpretation by the patients.

Other cancers, like breast cancer, have more specific signs and this can lead to fewer problems with misinterpretation and misdiagnosis.

4.7 Influence of the community

Influence by family members and neighbors was mentioned by many patients. Up to now, this influence was mentioned in the chapters `triggers for action´ and `contributing factors´. In this chapter I want to look more closely at the role others played on the patients´ pathway to treatment.

4.7.1 Person of trust

The person of trust is defined as the person with whom patients first share their experienced bodily changes or their diagnosis (table 9).

Table 9 - person of trust

	number	percentage
husband	15	39.5%
children	20	52.6%
family other	1	2.6%
friends	9	23.7%
noone	6	15.8%

A majority of the patients related to their family: their husband, children or both. *"I talked to my husband and my children. I said that I see my period again, but that I did not have seen it for 5 years. We discussed it and everyone agreed that I have to see a doctor." (Patient 27)*

9 (22.5%) of the patients talked to friends about it. *"I did talk about it with my friends and they told me it might be some kind of sickness, they advised me to seek medical treatment." (Patient 14)*

Others did not talk to anybody at all. *"I don't have a husband or children, my husband died a long time ago and my son who was young was killed by people trying to rob him, I have no one, so I haven't discussed it with anyone I kept it to myself, so I went to the health center because I had no one to consult." (Patient 13)* This woman did not have anybody she could share her experience with. So she decided to consult a health care professional. Others did not talk to anybody because they did not know what to tell their family and friends. *"No I didn't. What should I have told them? I did not know what my problem was. So I kept it to myself." (Patient 35)*

Even though most patients involved others, often some time passed until they opened up. While some patients first observed their bodily changes for some time until they involved family and friends, others did not talk to anybody until they were diagnosed. *"I didn't tell anyone, and then a mixture of blood and white fluid started to come out, I didn`t go to hospital for some time, I didn't have any money, I told my daughter after some time and she asked me when it started and I told her it has been some time, and she took me to hospital." (Patient 8) "After being examined by the doctors I told my husband and he was the only one who knew at that time." (Patient 17)*

While most patients involved those who are the closest to them, 2 (5%) patients specifically chose certain friends, because they worked as health professionals. *"Normally I live in AA, but at that time I was there. So I called my friend she is a doctor from Gondar and she advised me to talk on the same day to the doctor. She gave me the name of a good doctor." (Patient 36)*

4.7.2 Support by community

Generally, family and friends play an important role in Ethiopia. Support in everyday life is common and in extraordinary situations like a sickness this role becomes even bigger. This support can be emotionally, advisory or physically.

Patients with cervical cancer were faced by a new extraordinary situation. Their whole life changed within an instant. Patients explained a lot of worries and fears they have to face. In this situation family and friends did give an emotional support. *"The thing is when you have children, I have four children, so first I wasn't comfortable to try it and it is upsetting when you have children and when you are faced with this kind of disease, so I was in a dilemma but my children encouraged me, so I decided to try it for one time and then I will decide." (Patient 6)* This patient did not have to face the situation by herself and could discuss her worries with her family members. This quote also showed that advice is given and the patient got support to make a decision. Other examples were earlier discussed in the chapter `triggers for action`.

But the major support was given in the background while patients were in this difficult situation. *"They [neighbors] do, they always come out and help us, when we are in need." (Patient 9)* Thus, friends and family looked after the patient. Many patients also found a possibility to stay with relatives while they had to be in AA. *"But my sister lives here with her husband and also her children. So I can stay with them and they also support me. They bring me to the hospital and wait with me. And they give me food. I try to help, but especially when I got the therapy I was so tired that I could not help them and I was so weak that they had to help me with everything." (Patient 39)*

Furthermore, patients also got financial support. *"I live in a woreda and most people know me, so they know, even when I had no money I asked people to give me some for treatment, they helped, the kebale wrote me a letter for free treatment, they helped me a lot." (Patient 2)*

4.7.3 Discouragement & Discrimination

Examples of discrimination and discouragement were given during the course of the interviews. In some cases patients experienced that people from the community withdrew from them and showed that they were afraid of coming into close contact with the patient. *"This is a little bit hard, they exaggerated it, and they assume that it will be transmitted to them easily. … Yes it has happened, both from my family members and also from my neighbors." (Patient 1)* Another patient made a similar experience. *"Sometimes people act differently, sometimes when some kind of bad smell comes they turn their face, I see them changing their facial expression, sometimes they hide their nose with things and walk away, this is not a good thing, this should be changed, I also feel it, that is sad." (Patient 2)*

But it was not only this direct discrimination which patients had to face. The disease was connected with sexual intercourse and people tended to make connection between the development of cancer and sexual intercourse outside of the marriage by both husband and wife.

"They assume it is because I have a lot of children, so they talk behind me about this and the other thing is about my husband, he is a driver so they associate it with HIV assuming that he might have other relationships on the side, but now I think the rumors are fading." (Patient 17) In this case rumors were spread against both husband and wife. But also the husband got suspicious against his wife. *"He was really sad when he heard it, he was suspicious but after some time he understood it, but he was sad in the beginning, we are still together." (Patient 17)*

One further issue which came up was a big uncertainty towards radiotherapy. 1 (2.5%) patient remarked that she was afraid of radiotherapy. "*People tend to discourage you, they tell you the problems." (Patient 6)* Another patient made a similar experience. *"Before I started the treatment people were telling me that the radiation will create some damage and some bad odors, I was afraid." (Patient 1)*

Also from family side, discouragement took place. *"He has no idea, and he was worried about me, when they told me that I will take radiotherapy he was worried that I might not survive it, he advised me not to take it but I told him that I would take the risk of dying then he supported me." (Patient 17)*

These examples showed that not only patients were afraid, but also their family members. They faced similar worries and discouraged patients with their behavior.

4.8 Knowledge about cervical cancer

4.8.1 Previous knowledge about cervical cancer

Only a small number of patients had heard about cervical cancer before they were diagnosed with it (table 10).

Table 10 - previous knowledge about cervical cancer

No	27	67.5%
Yes	5	12.5%
n/a	8	20.0%

Only 5 (12.5%) of the patients had heard of cervical cancer. 3 of them had heard about cervical cancer on television. *"I only heard about it on TV, they were saying blood discharge can be one symptom, so when I saw it I went straight to the hospital and now I am here,… I saw it on ETV, in talk to the doctor program." (Patient 14)* While this woman heard about it on Ethiopian channel, another woman got information from an US channel. *"Yes I have. I heard about it in the TV on an American channel. But I thought it is a problem in America, and not in Ethiopia. I had never heard about someone being sick from it in Ethiopia." (Patient 27)*

The other 2 patients did not specify where they got their knowledge from. *"I used to hear about it, I am a teacher and I read, so I have heard about it but I didn't have the understanding that people can survive it, I only had small information." (Patient 17)*

From those 27 (67.5%) patients who had never heard about cervical cancer, 5 had heard about other cancer. *"No I haven't. I heard of cancer and I knew it can develop out of different things, lung, breast, but I didn't know what the cervix is before, so I also did not know that cancer can develop from there. Now I`ve seen many women with the same disease and I wonder how it is possible that I had never heard of it. It must be common in Ethiopia." (Patient 31)* Another patient also explained that she had heard about cancer before from the radio and that cancer is becoming common in Ethiopia. *"I had heard about cancer and they said in the radio that more people get cancer in Ethiopia."(Patient 31)*

4.8.2 Knowledge about cervical cancer after diagnosis

It was shown that patient had little knowledge about cervical cancer before they were diagnosed with it. It could be assumed that patients have better knowledge after they are diagnosed and start therapy. However, the interviews showed a different situation.

"I don't know what I have, all I know is I am sick." (Patient 15)

This explanation was made by a woman who was diagnosed with cervical cancer and was about to start radiotherapy. Other patients also showed that they did not know from what they were suffering from, even though they were already diagnosed with cervical cancer. It occurred to me that some patients were not interested in understanding what they are suffering from, instead they just followed the doctor`s advice. *"They told me things to do like go to black lion for further test, then when I finished that they told me I will be better if I came here and if I take this treatment, so I just do what they told me." (Patient 20)*

However, other women showed that it was important for them to know more about the disease. *"What I believe is that I have to know what things to avoid for the disease not to re-emerge, for example some people say I should avoid having sex, for a year or more, I want to know this kind of things, what foods to eat and what foods to avoid, if I know these, I will not be worried about anything." (Patient 2)* While this woman put the focus on protecting herself, another woman underlined the importance for others to know more about the disease so it can earlier be detected. *"I think the people need more information. People have to know what the symptoms could be so that they know that they should seek help." (Patient 31)*

Awareness towards cervical cancer and cancer in general seemed to increase after diagnosis. While most patients had never heard of cervical cancer beforehand or of other cases of cervical cancer, they hear about other woman suffering from it after diagnosis. *"No I haven't but since a year ago I have been hearing about it, I heard about it from other people, I have heard how bad it is, I have heard about it." (Patient 12)*

4.8.3 Perceived cause of cervical cancer

Participating women gave a wide range of possible causes for their development of cancer. Grouping the causes named by the participating women I found eleven different groups of causes (figure 11).

Overall, 11 (27.5%) of the patients could not think of any cause which could have led to the development of their disease. Some of them did not think that it was important that they know where it came from. *"I don't know. I don't understand these things. And I think it doesn't make a difference where it comes from. Now I had it and it is gone. That is important for me." (Patient 39)* Another woman thought that god will know and so she did not have to know. *"I don't know. Only god knows. He will know why I got it." (Patient 35)* Others did not find an answer even though they thought a lot about it. *"I don't know. I have thought a lot about it. But I don't know." (Patient 24)*

Looking at the different causes, which were brought up by the other patients, it could be seen that they can be differentiated between causes which are due to external conditions, like living circumstances and internal causes which had their origin inside the body of the woman.

14 (35%) of the women named causes which I grouped as internal causes. In 3 cases women related it to their use of hormonal contraceptives. Different reasons for the relation between usage of hormonal contraceptive and development of cancer were mentioned. 1 woman saw a mechanical reason for the development of cervical cancer: *"I think it is because of my use of contraceptives, I used to use loop, a loop was in my womb for seven years, the loop eventually got covered by my flesh, … , she (the doctor) was very sad and she took it out and it started bleeding, … , I was fine after that but I think it was not healed completely, so I think this is the reason for it"(Patient 5).* The other women connected the cancer more to the general effect of hormonal contraceptives. Unlike the first mentioned patient, she used the pill and not a loop. *"I used to take contraceptive tablets, I used it for 4 years, I think it is because of that." (Patient 6)*

Pre-existing diseases were mentioned in 3 (7.5%) cases as a possible cause. These pre-existing diseases varied: 1 suffered from hypertension, 1 from a variety of diseases and 1 from STDs. *"I also do have hypertension so they also gave me medicine for that, I think it is following the hypertension that I got this other disease." (Patient 12) "I was not always clean down there and I also was sick before in that area. I sometimes had to take medicine. So maybe it developed from there." (Patient 32)*

In 2 (5%) cases women saw an infection as the reason. *"I think it is kind of an infection. Women get it from men. But it only grows in women." (Patient 36)* Hereditary reasons were another cause mentioned by 2 (5%) women. *"I have heard that something is wrong in the genes of those who get cancer. So I think you just get it because you are a little bit different." (Patient 40)*

The last group of causes on the internal side which was mentioned by women was parity related. While 3 (7.5%) women related their cancer to the large number of children they got, 1 (2.5%) woman thought that she got cancer because she did not have any children. *"I don't know, but I guess it is because I gave birth to a lot of children, I got married when I was 15, and I had children so I guess it is because of that." (Patient 17)* "*I think this is because I could never get a child. I was five times pregnant; two times with my first husband and three times with my second. But I lost all the children." (Patient 26)*

In terms of external conditions causing cervical cancer, the majority of women mentioned reasons related to their living circumstances. The two groups `hard work´ and `simple living conditions´ fell into this area. Hard work was related to work on their field, carrying of heavy loads and caring for many children. The group `simple living conditions´ describes sanitary problems as well as uncomfortable sitting area. *"I have no idea, maybe it is because I work so hard, I never quite, I work in the sun, I work a lot, and I might also be related to not using the toilet properly, or maybe because I* *don't choose where I seat, I sometimes seat in a very hot stone, …, but when it comes to sitting I don't really chose where I should, I sleep in uncomfortable places, sometimes when I am tired I sit in a hot stone thinking it is under a shade, and we farmers don't build a good toilet so sometimes I sit in a hot, open toilets, I think this are the reasons for it." (Patient 2)* This woman described what the living conditions in rural Ethiopia were like and named hard work, sitting places and toilet problems as well as her simple living conditions. Another woman described in depth what she understood as hard work. *"I don't know, maybe it is because I work hard, I had ten children and I still don't rest I work hard around the house, that is maybe the problem." (Patient 4)*

2 (5%) of the interviewed women saw a shocking event as the cause for the development. In one case it was the death of her son and in the other case, the death of her mother. *"I have no idea; I assume it is because I was shocked by my son's death, that's what I think." (Patient 8)* Another patient also saw a specific event as the cause for her cancer, but in her case it was an accident; she fell on the ground and hurt herself. So this event had to be separated from the events mentioned above. Those caused mental pain while in this case it led to a bodily pain. *"Maybe falling on the ground, or walking for a long distance, but other than this I don't know why and how, but I always think about the falling incidence." (Patient 11)*

Working as a prostitute was seen by 2 (5%) women as the reason. *"I used to work in hotel as a prostitute, so I think it is caused because I was careless sometimes, I worked as a prostitute for ten years." (Patient 1)* Her job as a prostitute implied that she had sexual intercourse with many different partners and she also mentioned that she did not always protect herself by using condoms.

Finally, breaking taboo is mentioned by 2 (5%) patients. *"It is because of `mech´, she was making `engera´ and she stepped out for a moment outside, and she returned and continued making `engera´ and that's when she caught it." (Patient 9)* Making `engera´ was traditionally a work for women and they were not allowed to interrupt their work and go outside in the sun. This woman broke this role and afterwards she developed cervical cancer.

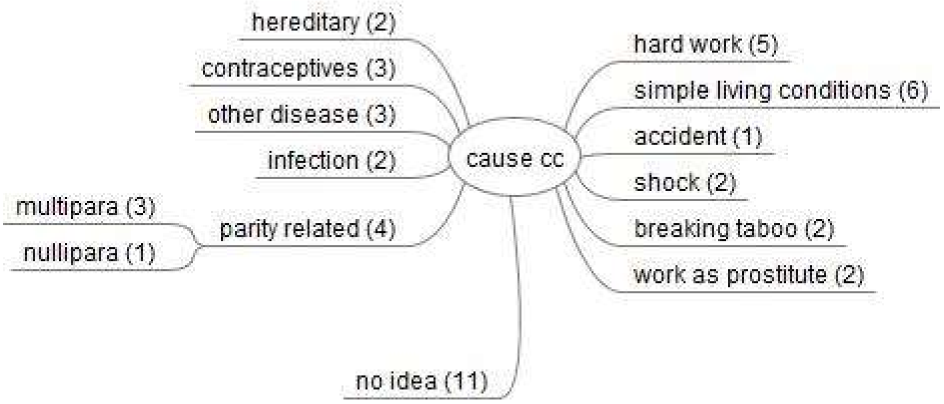


Figure 11 - Perceived cause of cervical cancer grouped by internal and external causes; quantity cause mentioned in brackets

All patients who have found a reason could explain why they thought of that specific one. However, only few of them were according to those mentioned by the WHO (WHO):

- Infection with HPV – `infection´(n= 2)
- Multiple sexual partner - `work as prostitute´(n= 2)

Considering that all women were diagnosed with cervical cancer at the time of the interview, these results underlined even more how little knowledge patients had about cervical cancer. Furthermore, it had to be considered that seeing a cause for cervical cancer in contraceptive use could, when shared with the community, interfere with family planning modalities.

4.9 Psychological challenges

On top of all the barriers accessing treatment patients also faced psychological challenges along the pathway to treatment.

"I don't see anything, I think no one wants to help us, I don't think there are a lot of choices to get treatment, I am still sick. I was being treated a year ago but I am still sick" (Patient 19). This statement showed disappointment in the health care system and the doctors. It also showed the lack of options patients face when they find themselves in that situation.

Patients interviewed mentioned many different worries they were facing. Often the fear of death was mentioned. The patients interviewed had little knowledge regarding their disease, as was mentioned in the chapter `Knowledge Regarding Cervical Cancer`. This made it difficult for the patients to understand where they stand: do they have a good chance of survival or is the treatment just for pain relief?

This left the patients in constant anxiety; a constant fear of death, fear of leaving their children and family behind, finding themselves in a situation which was difficult for them to understand. *"I worry a* *lot, I worry about death, about how I can continue to live like this, about my children, about the pain." (Patient 19)*

One further aspect mentioned was the incapability of living their normal life. The disease had weakened them so much, that walking and fulfilling daily routines had become difficult. *"I am worried, god is the one who is keeping me alive, god will decide when I will die, I am unable to do a lot of things such as, I can't walk by myself, I can't do things around the house, so I am so worried." (Patient 12)* It was not only a concern for them that they could not care for themselves; furthermore they also could not care for others close to them. "*I`m worried that I will die. But I'm also worried that I will stay sick and that I cannot care for my husband. He needs me a lot. Who should get the water, if I cannot carry it? Also, the pain is terrible. It constantly reminds me, that I'm not well and then I worry again." (Patient 30)* Furthermore, they worried about the financial burden. Since many women come from outside Addis Ababa they had expenditures for housing and food as long as they were waiting for treatment or receiving treatment and, on top of that, they were incapable of earning money at that time. "*I worry a lot; I am always worried that I will not get money for food and a place to live." (Patient 13)*

Insufficient pain management seemed to aggravate the situation of the patients further more. They were afraid that pain might increase or the pain had already got worse and it accompanied them day and night. *"I always worry, why won't I worry, I might die at any moment, I cry most of the time, I ask god to heal me and I am always afraid, nowadays the pain is getting worse than ever and the medicine is not really helping so I can't sleep at night, I spent the night worrying about the pain, my family, and life in general, so I worry a lot." (Patient 21)*

The fear for their lives, of leaving their children behind and the inability to cover costs, sometimes collided with the fear of radiotherapy. *"The thing is when you have children, I have 4 children, so first I wasn't comfortable to try it [radiotherapy] and it is upsetting when you have children and when you are faced with this kind of disease, so I was in a dilemma but my children encouraged me, so I decided to try it for one time and then I will decide." (Patient 6)*

It seemed that the patients had to make important decisions for their life, such as treatment decisions, but at the same time they found themselves in an exceptional situation. They were facing a life-threatening condition; often they were forced to stay away from their family, cover extra expenses and were not able to work at home all at the same time. As some patients mentioned, they turned to god and prayed for their survival. But how they really coped with this situation otherwise, remained uncertain.

4.10 Reaction by patients

After being diagnosed with cervical cancer and being treated, 5 (12.5%) of the patients explained that they wanted to teach the community about their disease. *"I used to hear about it, I am a teacher and I read, so I have heard about it but I didn't have the understanding that people can survive it, I only had small amounts of information, but now since I survived I educate people around me, that it is treatable, I am also a member of the Ethiopian Cancer Association." (Patient 17)* This patient wanted to help future patients on their way to accessing treatment. She herself said that, beforehand, she did not know that it was possible to survive cervical cancer, but now things have changed for her. The same patient had already started to talk to other people about her experience. *"I know one and she was afraid to seek treatment, then I explained about it and I told her 'I survived and you can survive too' but she was afraid of radiotherapy and she went to a traditional medicine place, but she died after some time."*

One of these women started with her friends and family. She told everyone she knew about her situation and also that she survived the cancer. *"I told all my children and all my friends. I want people to know. I want my people to understand what is happening with me and I also want everyone to know that cancer can get treated. In the beginning that was difficult for me. I was afraid, that people would be afraid of the disease. But everyone is very helpful and they worry about me. So, I'm happy that I told everyone. Now people learn and I hope they will also go to hospital when they are sick." (Patient 33)*

Another woman put her focus also on the support of patients. "*But now I have seen how many women suffer from it. Many of them do not get as much support as I get. Some sit completely alone in the hospital and there is no one with them. They are very afraid that they will die and they are afraid of radiotherapy. So I try to explain them and take the fear away from them. Some don't even know that they have cancer. I want to join the cancer association, so that I can teach other women about the symptoms and especially that it can be healed. So people don't lose hope." (Patient 27)* Even though, similar to the other patients, she wanted to create awareness about the possibility of survival, she also underlined the fact that many of the patients did not get enough emotional support.

These five patients were examples of one of the possibilities to creating awareness in the community. All of them put a focus on the possibility of survival. Educating people about signs and symptoms of cervical cancer, which could lead to early detection, is not mentioned by any of them. This issue was raised by one patient also quoted above (`knowledge about cervical cancer after diagnosis`). But she also complained that she did not know about these things, so that she could not spread this knowledge throughout the community.

4.11 Applying the health believe model

The health believe model (figure 12) was a model which was developed to predict and explain health behavior (Rosenstock et al., 1988). It described different variables which influence the perceived threat of a disease and thus, led to a certain likelihood of taking a recommended action.

The perceived threat arises from the perceived susceptibility, the perceived severity, the perceived benefits and the perceived barriers. The likelihood of taking an action is furthermore influenced by modifying factors: on the patient side like demographic variables and socio-psychological background, and on the provider side with awareness campaigns and knowledge of a disease.

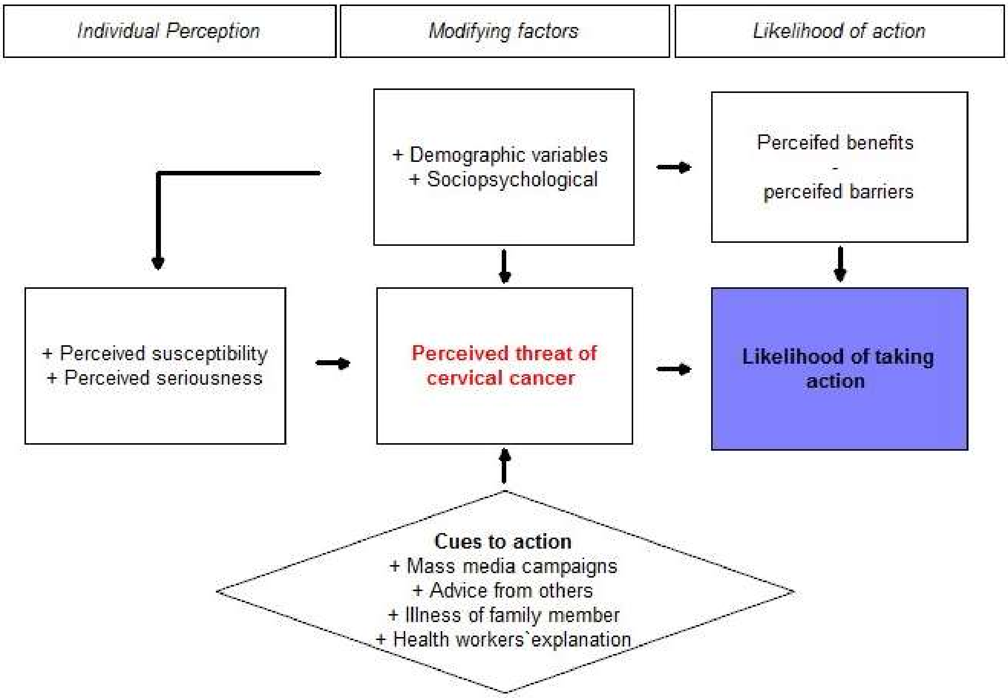


Figure 12 – Health believe model modified according to Rosenstock et al.

Since the health believe model is a model to describe health behavior, it can also be applied in the health-seeking behavior of cervical cancer patients in Ethiopia. I have separated health-seeking behavior in different intervals, as was suggested by Andersen and his colleges, and also the health believe model can be applied in these different intervals, since they all lead to a different action.

As shown in figure 13, those factors which were mentioned by the patients, influencing their pathway to treatment, are shown. These factors can be positive and are marked in green. All these factors were discussed in depth in the chapter `Triggers for action´. On the other side, marked in red, those factors which were barriers to treatment are displayed. These points were discussed in the chapter `Reasons for delay´.

These points varied in the different intervals and, looking at the health believe model, patients had to see a greater benefit in taking a certain action than the perceived size of the barriers. The whole pathway of treatment is surrounded by those factors discussed in the chapter `Contributing factors´. These were the same for all intervals and varied individually with each patient. However, three issues seemed to have a major influence from the patient factors:

- Support by family and friends
- Medical awareness and knowledge
- Financial security.

A problem which was related to cervical cancer was the fact that it presented with unspecific cancer signs. This led to problems in diagnosis and interpretation.

Looking at the different points in the figure, it could be seen that many different variables influence the pathway of treatment. On the one hand, patients themselves played an important role. Their interpretation of the situation had a great influence on their behavior. On the other hand, was the role of the providers. Accessibility of health facilities, treatment availability and the health care workers´ knowledge also had a great impact. These two sides were overshadowed by cervical cancer itself with its unspecific and late signs and symptoms.

However, the figure also showed that this pathway of treatment can be influenced by cues to actions. Those, mentioned by interviewed patients, were:

- New information on signs of cervical cancer from media
- Sharing experience with other patients
- Learning about other cervical cancer patients.

This showed that already some aspects existed in Ethiopia which fell into the area of awareness creation and it also showed that this creation could be successful. It also showed that patients with cervical cancer played an important role. They could talk about their experience and showed other women that cervical cancer can be treated. They could take fears from patients by sharing their experience about treatment availability and treatment options. If they knew more about etiology and signs of cervical cancer, they could also share this with others.

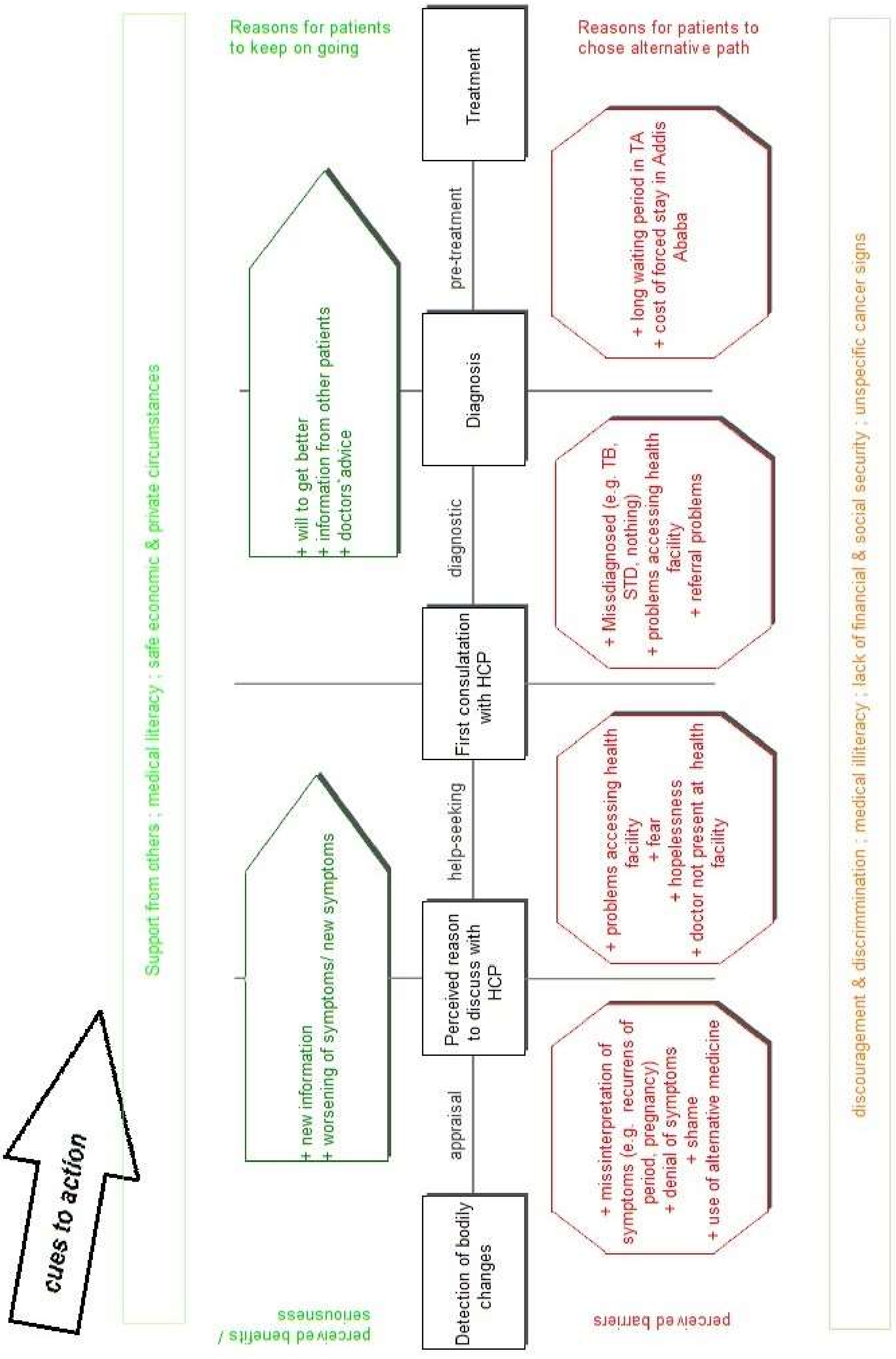


Figure 13 - Health believe model applied on the model of pathway to treatment for cervical cancer in Ethiopia

5 Discussion

5.1 Summarizing main findings

This study showed that cervical cancer patients faced a lot of challenges when they were looking for treatment. In all steps towards receiving treatment they faced a lot of barriers. These occurred both on the patient side, especially regarding right interpretation of their signs and social difficulties, as well as on the provider side, with misdiagnosis, referral problems and insufficient treatment availability.

On both sides, a major obstacle was a lack of knowledge regarding presentation of cervical cancer and its treatment possibilities. While patients did not take their bodily changes as serious, and if they recognized these as being serious did not know that they can be treated, health care providers did not interpret presented symptoms as related to cancer and did not seem to know how and where to treat it in an appropriate way.

On the other hand, positive aspects were also identified. Women were motivated to teach other women about their experience with cervical cancer and to make them aware of this growing health issue. Furthermore, most patients gained a lot of support from their friends and relatives. They helped them all along the pathway, pointing out the seriousness of their signs, joining them on their multiple trips to health institutions and offering housing and care in AA, while patients received radiotherapy.

5.2 Main findings

Cervical cancer is still a neglected topic in Eastern Africa and also in Ethiopia. However, in recent five years publications regarding cervical cancer have increased.

Main focus was put on screening methods, implementation of vaccination programs and HPV genotypes. A main obstacle in tackling cervical cancer was limited knowledge and awareness regarding cervical cancer in both normal population and health professionals. But studies from Sub-Saharan Africa showed that implementation of programs could be cost-effective and, using the example of Rwanda, promotion of cervical cancer awareness could help to successfully implement a vaccination program. Nevertheless, screening uptake remained lower than expected.

Those studies which looked at the perception of patients of cervical cancer found numerous challenges for the patients. With little screening uptake many patients presented in advanced stage of cancer. Furthermore, fear of pain and stigmatization, difficulties to access health centres and an immense financial burden were common challenges mentioned by patients.

The in depth interviews of this study focused on the perception of cervical cancer and the pathway of treatment from cervical cancer patients in Ethiopia.

Common first findings, found in this study, by the patients were unusual vaginal bleeding, abdominal and back pain, heavy white discharge and fatigue. Similar findings were made in a study in Ethiopia, where 38.5% described unusual vaginal bleeding, 29.5 % unusual heavy discharge and 15% pelvic pain (Tadesse, 2015) and also with studies from Tanzania and Uganda (Mlange et al., 2015; Mwaka et al., 2015; Mwaka et al., 2014). In this study, unusual heavy discharge was less common than in other studies. Only six of the patients described it as a first signs and overall ten experienced unusual heavy discharge. This difference might be due to a lack of awareness by the patients or due to the larger study population in some of the other publications. Another explanation could be that I counted mixed discharge as unusual bleeding. Nine of the patients experienced unusual bleeding mixed with white discharge. Putting these patients together, 15 (37.5 %) of the patients would have complained of unusual heavy discharge. All three signs are also described by the WHO as being common signs and symptoms of cervical cancer. (WHO) Further along the path, patients experienced other symptoms. Mainly pain became a very common sign. Along with this, vegetative symptoms like tiredness, weakness, loss of appetite became much more common. These vegetative symptoms are also described in a study from Uganda. (Mwaka et al., 2014)

The majority of patients did not interpret these findings as being abnormal. Some of them just did not think it was anything at all, others mistook it for their period, a pregnancy or associated it with external events. In other studies, similar observations were made. Mwaka and his colleges found in Uganda that first signs are often attributed to STDs or other conditions. (Mwaka et al., 2015; Mwaka et al., 2013) In a study from Kenya, it was shown than women often did not perceive the necessity to take signs seriously. *"They often confused the symptoms as minor issues that would soon go away, for example, lower abdominal pains."* (Ngutu & Nyamongo, 2015)

When patients perceived their symptoms as being serious the majority of them accessed a health institution at the primary health care level. Similarly, in Kenya, patients most often first accessed an institution at the primary level, followed by an institution at the private sector, then at the secondary level, and lastly a traditional institution. (Were & Buziba, 2001)

After accessing the health system, patients visited a median of four HSs, the last being TAH. These visits to the HSs were either to different HSs or visits to the same HS occurred. This is one more visit than planned inside the Ethiopian health system. (WHO) In another study from Ethiopia, patients had a median of two visits to HSs before they were referred to TAH. (Tadesse, 2015) However, these findings also showed a wide range of visits before being referred. Visits ranged between one and six visits to different health institutions. In a study from Tanzania, no exact data could be excluded regarding the overall visits of the patients before being referred, but it shows that a majority of the patients had three or more visits to HSs before referral took place. (Mlange et al., 2015)

Most often revisits to HSs on the same level took place and prolonged the referral process. Only one example for downward referral was found in this study. Most commonly, suspected diagnosis of cervical cancer was made in the secondary level. After a suspected diagnosis of cancer, not all patients were directly referred to TAH, the only health facility offering appropriate means of treatment. In a study from Kenya, problems inside the referral system and awareness of appropriate treatment facilities were also reported (Kivuti-Bitok et al., 2012).

But problems in the referral process were not the only difficulties arising on the provider side. In this study misdiagnosis with STD or other infections and period irregularity were common. In another study from Ethiopia, misdiagnosis occurred in 75% of patients (Tadesse, 2015). Patients reported incidents of misdiagnosis with STDs, gastritis and kidney diseases. The same problem occurred in other countries in Eastern Africa. In Uganda it was found that *“some people were treated for other conditions, often over a long time, and this may have led to delayed diagnoses and initiation of appropriate treatment”* (Mwaka et al., 2015). Similar findings were made in other studies in Kenya (Kivuti-Bitok et al., 2013) and Uganda (Mwaka et al., 2013).

Using traditional medicine was common among patients. However, most of the patients described traditional medicine as a supplement to orthodox medicine. During their waiting periods, they went to church for holy water or used traditional remedies. Only in a few cases patients used other forms of medicine before they visited their first HS. In these cases alternative medicine led to a further delay. These findings differ from results of other studies in Ethiopia, which suggest that traditional medicine played a major role inside the Ethiopian health system. They found that more than 50% of patients first relayed on traditional medicine (Birhan et al., 2011). Furthermore, they stated that no cooperation between traditional and modern medicine exist. Discussions with the community revealed that they trustrf in traditional medicine and expect better pain relieve than from modern medicine (Birhanu et al., 2012). These differences in findings might be due to the fact, that all studies had their focus on a different study population. Birhan and his colleges interviewed traditional healers and their patients, Birhanu and his colleges focused on the perception of cervical cancer of the healthy community and I focused on patients with cervical cancer who found treatment in TAH. A study conducted with the community in rural Uganda showed that they believed in both means of medicine: traditional and orthodox. (Mwaka et al., 2014)

Time passed between recognition of initial sign and start of therapy was an issue in this study and also in others. In general, I found that more time passed than necessary at each interval on the pathway to treatment. Following time intervals had to be interpreted with care since there existed no certainty for their accuracy. Patients guessed these intervals, often month or years after therapy started and no written data of certain dates existed. In this study mean values for appraisal interval was ten months, for help-seeking interval eight months, for diagnostic interval seven months and for pre-treatment interval six months. As a total minimum delay as perceived by the patients, I estimated as 19 months.

It is difficult to compare these numbers with findings from other studies since in most studies no specific models are used or only some intervals are described. Regarding the total time from initial sign to start of therapy other studies suspected similar time intervals: a median of 20 months (ranging from 2 – 140 month) in Uganda (Mwaka et al., 2015) and a median 1.5 years in Kenya (Kivuti-Bitok et al., 2012). In Ethiopia, the time frame for certain intervals were found in other publications. Diagnostic intervals was assumed to take an average of five months and the pre-treatment interval was assumed to be between three and seven months (Tadesse, 2015). In another study the pre-treatment interval was stated with an average of 3.8 months (Kantelhardt et al., 2014). Data from the last study was obtained from the patient files, so this data can be assumed to be close to reality. A study from Kenya gave a time frame for the appraisal interval as an average of 8.2 months (Were & Buziba, 2001).

Some reasons were found in this study which prolonged the intervals in the pathway to treatment. Reasons were found in every single interval and they were found on both the provider side, as well as on the patient side. Main reasons on the patient side were misinterpretation of symptoms and problems accessing and staying at health institutions. Other reasons mentioned were shame and hopelessness. These problems were also mentioned by other studies from Ethiopia. While Tadesse saw further difficulties in lacking financial security and great distances to health institutions (Tadesse, 2015), a study by Birhanu and his colleges identified the fear of stigma related to not visiting HS (Birhan et al., 2011). Similar reasons for delay were also mentioned in studies from Eastern Africa. (Mwaka et al., 2013; Ngutu & Nyamongo, 2015; Kivuti-Bitok et al., 2013; Mlange et al., 2015)

Major problems on the provider side were misdiagnosis and referral problems, as mentioned above, and the long waiting period inside TAH. The long waiting period in TAH was also observed by Tadesse and Kantelhardt et al. In Kenya similar problems were found at the provider side: heavy workload, unskilled health care providers and insufficient treatment facilities (Kivuti-Bitok et al., 2013).

Looking at the patients´ pathway of treatment, it became obvious that there are not only reasons which led to delay, but also reasons which motivated patients to seek care or certain triggers which lead to actions. Main triggers for actions were worsening of signs or appearance of new signs and the support from others, helping patients not only to seek care, but also bringing in new information and thus, offering a new interpretation of signs. Birhanu and his colleagues found that one major trigger for action was intolerable pain (Birhanu et al., 2012). This triggers for action was also mentioned in two studies from Eastern Africa. While one study in Kenya showed that patients access care when signs worsen (Ngutu & Nyamongo, 2015) the other study from Uganda found the following: "Prompt help-seeking was often triggered by life threatening, persistent or worsening symptoms, the appearance of new symptoms, or a lack of response to self-treatments" (Mwaka et al., 2015) Later in that study, they also find evidence of the positive influence others can have on the patient: "Reinforcing advice often fostered immediate help-seeking."

Influence of others on the pathway of treatment seemed to be an important issue. Therefore, I also looked at the person of trust, meaning that person which the patient first talked with about her situation. In this study most patients first talked with members of their family about their situation, either their children or their husband. Similar observations were made in Kenya where 90 % of the patients first talked to a member of their family, either their husband or a female relative (Were & Buziba, 2001).

The family also played a big role supporting the patients on their pathway to treatment. With no existing social system to support the patients, the family had to take this role: they have to pay for upcoming costs, support the patients inside and outside of the hospital and psychologically support patients in their situation. Most of the patients interviewed got this support and they seemed very glad about this.

However, some patients had to face discrimination and discouragement from both their family as well as from their neighbours and friends. This issue was discussed in other studies. "*They [focused group discussions] noted a cervical cancer diagnosis could cause blame or abuse between a woman and her husband. A majority of opinion leaders also noted women with cervical cancer may be unsupported or socially isolated from their communities*" (Friedman et al., 2014). In other studies, it was found that patients lacked financial and emotional support by their husband or were abandoned by relatives. (Mwaka et al., 2015; Mwaka et al., 2013; Ngutu & Nyamongo, 2015; Mwaka et al., 2015) It was also found in these studies that patients might have the fear of being talked about or stigmatized, when people find out about their situation.

Another aspect which influenced the whole pathway of treatment was the knowledge patients might have about cervical cancer. The majority of patients had very little knowledge about cervical cancer before they were diagnosed with it. Those who had heard of cervical cancer had their information mainly from the media. This observation was also made in other studies both in Ethiopia and in other countries in Eastern Africa. In Ethiopia 3 studies showed that even though the majority had heard of the existence of such a disease, specific knowledge was low and signs and etiology of cervical cancer could not be named (Bayu et al., 2016; Bezabih et al., 2015; Getahun et al., 2013). Those who had heard of cervical cancer had their information from the radio or health care providers. In Kenya similar observations were made (Ngutu & Nyamongo, 2015; Rosser et al., 2015; Rosser et al., 2014; Sudenga et al., 2013). At Sudenga´s study the main source of information came from health care providers.

Also, after being diagnosed with cervical cancer, the study population had very little knowledge of cervical cancer. This showed that patients received little information by health care providers. Similar findings were made in another study from Ethiopia (Tadesse, 2015).

When asking patients after they were diagnosed with cervical cancer about the cause of it, a variety of causes were given, but only few were according with cause and associated risk factors named by the WHO, being: high risk HPV infection, early first sexual intercourse, multiple sexual partners, tobacco use and immune suppression (WHO). In contrast, the majority of causes were found in the primitive living conditions or linked to other bodily conditions. In Kenya causes of cervical cancer were seen in poor hygiene or sexual behavior (Friedman et al., 2014). In Uganda the cause was associated with the civil war and those who knew about the presence of a virus thought that the virus exists from birth (Mwaka et al., 2014).

Patients of this study found themselves in a vulnerable situation. They faced a life-threatening disease, had little knowledge about this disease and had to rely on a health system which was difficult for them to understand; often accompanied by insufficient pain management. This led to a constant fear of death and worries related their living circumstances and family. A similar picture was drawn in all other studies related to this topic in Ethiopia and in Eastern Africa. I could only agree with the common conclusion that more effort had to be done in order to support cervical cancer patients: Expansion of treatment facilities and of pain management, creation of awareness for cervical cancer in the community, but also among health care providers and involvement of the patients into the treatment process seemed to be necessary first steps to slowly improve their situation.

5.3 Interpretation of main findings

In order to interpret the findings from this study a broader picture has to be drawn. Cervical cancer is one of the cancers which can be detected in a pre-cancerous state and then be treated easily. However, signs of cervical cancer occur in advanced stages of the disease. Therefore, means of prevention plays a major role in tackling this disease.

Implementation of prevention strategies played a major role in decreasing the incidence rates of cervical cancer in Europe. Some countries in Sub-Saharan Africa followed this path. Especially Rwanda has to be mentioned in this context. They implemented countrywide vaccination and screening programs successfully, achieving a 93% coverage in the target population (Binagwaho et al., 2012; Pathfinder International, 2010).

Ethiopia has not yet achieved this stage of implementation of prevention strategies. Awareness for cervical cancer is low amongst the population, health care workers and politicians. Slowly this is changing, but still a lot of work has to be done. This study showed clearly that little knowledge overshadowed the whole pathway of treatment. Patients and health care workers were not able to interpret signs and symptoms in the right way. Existing guidelines to treat STDs (WHO, 2001) when women present with unusual vaginal bleeding or discharge are strictly applied without looking closely at the patients, without keeping in mind risk factors for other diseases or further circumstances. This lack of knowledge further delayed point of diagnosis and made it more difficult to treat patients successfully.

General problems, arising from the fact that Ethiopia is a developing country, influenced the pathway to treatment even more. Patients faced transportation difficulties, lack of financial security and shortage of treatment availability. Looking at the one single existing radiotherapy department it became clear that this is not sufficient. I can only assume that help from other countries to tackle these shortages would be very welcomed and for the patients much needed. However, this is also connected with the motivation of the Ethiopian government to put more attention on this topic. Organisations, like Pathfinder (Pathfinder International, 2010) are willing to support them, to implement prevention strategies but they want to see that their effort is placed into a fertile ground stable enough to set up a long term partnership.

Raising awareness among the community and health care providers would be the first step to help tackle cervical cancer and also improve care for other cancer. People have to know that cancer occurs and also that it can be treated in order to accept prevention and screening strategies and seek help in the health system when they fear that they might suffer from it. On the other hand, a skilled team of health care providers who know how to diagnose correctly refer and treat cervical cancer, is essential so that patients receive appropriate care and feel that they are in safe hands. However, this can only be achieved with sufficient medical supplies.

As long as countrywide prevention strategies do not exist or are not used by the citizens, it is important to care for those patients presenting with cervical cancer to the health system. Considering cancer as a possible diagnosis is a first step towards earlier diagnosis and referral to the right point of care. Furthermore, explaining patients their situation could reduce their fear and make them more compliant. Additionally, they could work as messengers for the community and spread knowledge of cervical cancer.

5.4 Strength and limitations of this study

The main concern regarding qualitative data is that no general assumptions and conclusions can be made. All information gained and all ideas developed from this type of study are made from a personal perspective. This study can only show a small picture of a very complicated situation; it cannot give a whole image of the situation. This fact is underlined by the study population chosen. All patients participating were already diagnosed with cervical cancer. Thus, all of them managed to finish their pathway to treatment. The path taken by other patients suffering from cervical cancer, but who never got treatment, is not reflected in this study.

However, this individual perspective also has its strength. It gives a deep insight into personal feelings and experiences. Each woman had the chance to guide the interview into the direction which was important for her. With the open interview guideline, new areas of interest and new issues may easily get involved. This is the benefit of a flexible study design adapted to the information gained during the interviews.

Not all data gathered can be expected to be hundred percent true. In a retrospective study, patients might have drawn connections between events which they did not perceive at the time. Signs might be associated to cervical cancer which appeared beforehand or happened by incidence. Patients had often suffered a long time from cervical cancer before we interviewed them. Hence, some information might be forgotten or other events included. The main problem which I see regards events in time. Many patients did not know their age and lived in rural area not dependent on a calendar or official clock time. This made it particularly difficult to get exact time frames between visits to health stations or between the beginning of symptoms and a particular event. Since no medical data existed before arrival at TAH, previous time intervals had to be assumed to be incorrect. Therefore, intervals must be interpreted with caution.

Furthermore, patients were interviewed inside TAH and this might have influenced the interview content. Patients might have wanted to please the interviewer by giving the perceived correct information. This can be done in order to please the interviewer himself but also to please the doctors and nurses who were treating them. We always explained before the interviews that data will not be shared with staff of TAH during the time of interviews and that all data will be collected anonymously in order to decrease the impact of this bias. Another bias might be occurred due to the necessity of translation. Interviews normally took place in Amharic and were then translated into English. Some phrases were difficult to describe in English due to the cultural or religious background of the word. On the other hand, mistakes during the course of translation can never completely be excluded. To minimize this bias, translations were done twice and if uncertainties appeared, these were discussed. Furthermore, some participants were not able to speak Amharic and relatives stepped in as translator. In these cases the personal experience of the translator would have had an influence. Moreover, interviews were conducted by a male interviewer. Patients might have felt insecure talking about certain topics with a male person. We tried to reduce this impact with me, female, being present at each single interview.

Despite all these limitations, this qualitative study could identify a number of possible obstacles in the pathway from first symptom to treatment of cervical cancer patients. Application of models, especially the model of pathway to treatment, makes this data comparable with data from other studies. Time intervals are exactly defined and reasons influencing delay can be put clearly into a certain aspect of the pathway to treatment. This enables future studies to look more closely into these intervals and those barriers found.

5.5 Perspective for the future

Cervical cancer is an increasing problem in Sub-Saharan Africa (Bos et al., 2006). For a long time, focus was put on infectious diseases and accidence. With increasing life expectancy and decline of infectious diseases the burden of cancer increases. Even though publications regarding cervical cancer in Sub-Saharan Africa and also in Ethiopia are rising and cancer is getting more into the focus of science, few changes have been made within the health system.

I think it can be concluded from this study that the pathway to treatment takes more time than necessary and that patients face a lot of challenges. I think that future studies should not focus on the exact time passing, but on those barriers which hinder patients in receiving treatment. This study was conducted with 40 patients. It would be interesting to compare findings from this study with a greater quantity of patients. Also, accessing knowledge and practises of health care professionals on a greater scale in Ethiopia could clarify the dilemma and image of cervical cancer patients and of their treatment options. I am looking forward to reading the studies which focus on HPV genotypes to find out if implementation of existing vaccinations could be helpful.

However, certain conclusion can be drawn from this study. As the health believe model (Rosenstock IM, 1988) shows patients´ action can be influenced. Most publications regarding cervical cancer in Ethiopia and Eastern Africa suggest implementation of an awareness campaign. Looking at the findings from this study, I must come to the same conclusion. Data has shown that patient have little awareness regarding cervical cancer and its signs and symptoms. Positive examples were given that patients visited a health institution after they learned about the possible harmfulness of their clinical presentation. Also, patients explained that they think it is necessary that they and other women learn more about cervical cancer. However, it is important to set up a sensitive campaign to protect patients from exclusion and discrimination.

Another aspect, which I realized, was that the patients themselves could play a major role in creating awareness. As some patients said, they wanted to share their experience with others in order to teach the community about cervical cancer. But, also after diagnosis, knowledge regarding cervical cancer was low. Therefore, explaining about epidemiology, risk factors, signs and symptoms to patients could spread knowledge in the circle of friends and acquaintances.

Along with the above considerations, awareness of cervical cancer has to be increased among health care workers. Especially on the lower level of care, misdiagnosis was common. With increasing sensitization of health care workers that cancer, and cervical cancer specifically, can occur in Ethiopia, a faster diagnostic process could be furthered.

This study showed clearly that patients find themselves in a very vulnerable position. So far, patients mainly rely on their relatives and friends, financially and emotionally. Another aspect of a health care system is psychological support. Patients reported from their variety of worries regarding costs, their children, survival and the treatment in itself. Furthermore, pain relief was often not achieved. These two factors put a patient into a vulnerable position fearing for their life and suffering at the same time. These topics should be of concern for health care providers to support patients in their pathway to treatment.

6 Conclusion

Cervical cancer is a growing burden for the Ethiopian health care system and so far means to tackle cervical cancer in Ethiopia are rare. Vaccination programs are tested in pilot studies at the moment, few hospitals are offering some kind of screening program and treatment availability is low. In order to improve this situation it is important to understand what patients with cervical cancer think and which path they took to reach the hospital. Therefore, this study was conducted, aiming to explore in detail cervical cancers´ perception of the disease and to explore their pathway to treatment.

It was shown clearly, that women with cervical cancer face a lot of difficulties on their pathway to treatment. From first recognition of signs to the start of therapy they have to manage many new and difficult situations. Not all of these are direct side effects from cervical cancer. Their normal life cannot continue; they cannot fulfil their daily routine; they have to spend much money to reach health facilities and receive treatment. This is underlined by constant anxiety.

But also the disease in itself brings many challenges to the patients. It starts with the first recognized signs, like unusual vaginal bleeding and pain, which are often misinterpreted or patients are ashamed of talking about them. Further signs are often associated with a worsening of their bodily situation so that patients are forced to seek help. Competing medical ideas, between orthodox and traditional medicine, further complicate help-seeking processes.

Problems arise on both, the patient and the provider, sides and many of these problems are related to a lack of awareness. Patients have problems to interpret their bodily changes and health workers are not able to diagnose patients properly. Even after diagnosis patients have little understanding of their situation and cervical cancer in itself.

All these problems lead to more time than necessary passing, between initial sign recognition and start of therapy at TAH, even further delayed by long waiting periods at the only radiotherapy department in Ethiopia.

Despite all these problems arising for cervical cancer patients also positive aspects can be shown. Patients receive a lot of support from their family and friends all along the pathway to treatment: they function as nurse, as chauffeur, as psychiatrist, as hotelier and as bank. Furthermore, surviving patients are willing to share their experience with other women in Ethiopia in order to prevent them from making similar experiences.

This leads to the conclusion that existing screening and vaccination programs have to be extended in order to decrease the burden of cervical cancer in Ethiopia and find patients at an early stage.

Furthermore, findings from this study can be used to set up a sensitive awareness campaign, which describes possible signs and symptoms but also underlines treatment possibilities. Also, creating awareness among health care workers will help to diagnose patients at an earlier stage. Furthermore, involving patients into the pathway of treatment could help them to understand where they stand and what can be done. This could take an emotional burden from patients and at the same time help sharing accurate information with other woman.

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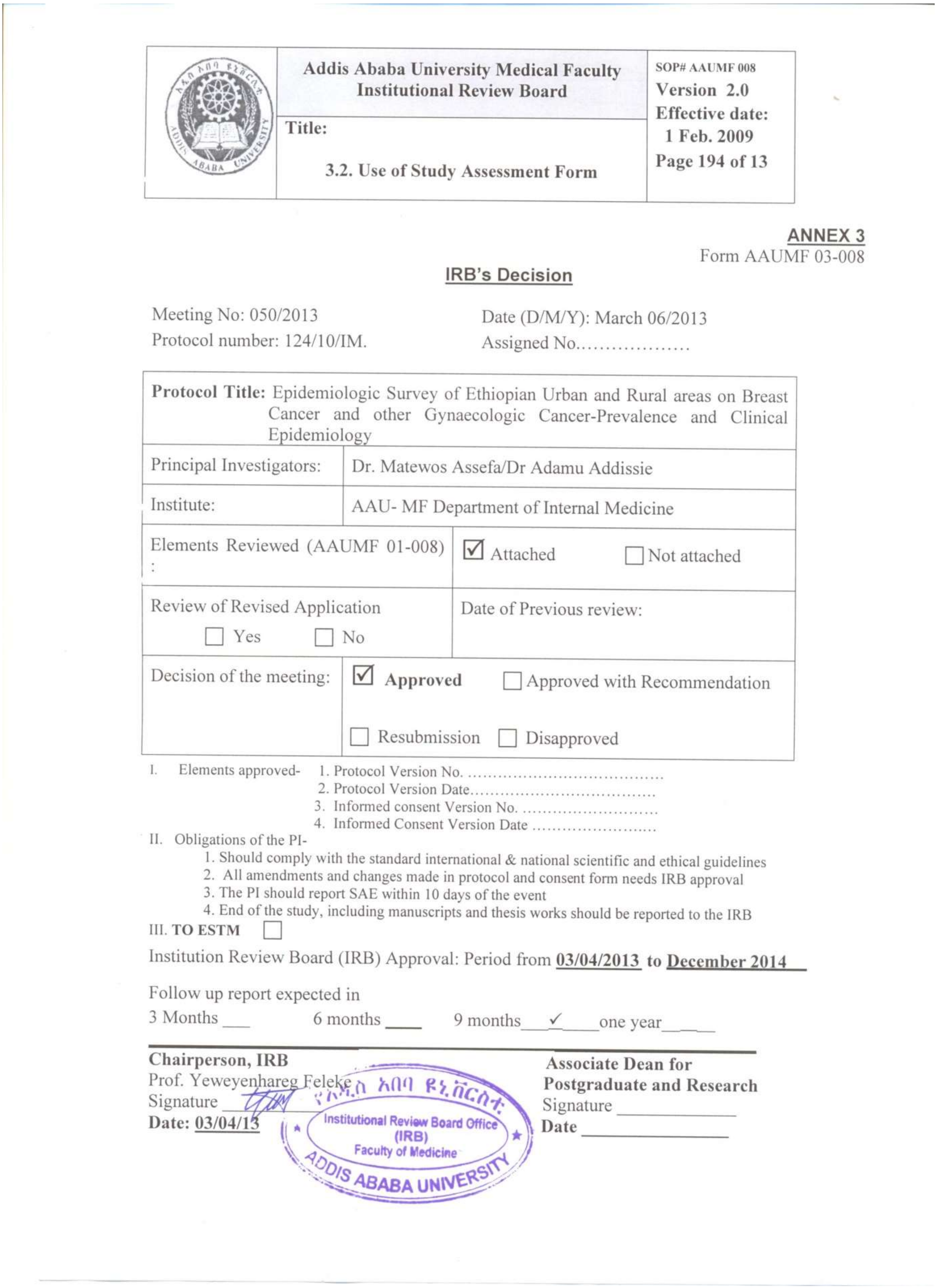
7 Theses

1. Existing literature regarding cervical cancer in Ethiopia and Eastern Africa showed that understanding and knowledge of cervical cancer, its epidemiology and treatment options are low amongst patients and health care providers. Furthermore, patients with cervical cancer have to face many challenges in obtaining treatment and also psychologically.
2. The pathway to treatment started with recognition of bodily changes and ended with obtaining treatment in Tikur Anbessa Hospital. Patients, who participated in this study, had a median of four visits to different health stations and spent more time than necessary along the whole pathway to treatment.
3. Barriers existed on the whole pathway to treatment, both before and after accessing the public health system. The main barriers which were found are misinterpretation of bodily changes by patients, misdiagnosis and misreferral by health care workers, economic concern and long travelling distances.
4. Support by family, friends and other patients played an important role in motivating patients to seek help and stay within the help seeking process. Furthermore, new information from media persuaded some patients to turn towards the public health care system. Worsening of signs or occurrence of new signs which interfered with their normal working routine was another strong trigger to seek help.
5. Knowledge regarding cervical cancer was low both before and after diagnosis. However, after diagnosis awareness regarding cervical cancer and other patients´ history increased and patients desired to learn more about the disease´s signs and symptoms.
6. Common first recognized signs were unusual vaginal bleeding and some sort of pain. Other signs experienced were heavy white discharge and vegetative signs. In the beginning these signs were often not interpreted as being serious or they were attributed to other conditions, like recurrence of their period or a possible pregnancy.
7. The community played a very important role supporting patients along the whole pathway to treatment: financially, psychologically and practically. However, patients are also at risk to be discriminated and discouraged by the community.
8. Both private health institutions and traditional medicine, like traditional healers and holy water, play an important role for cervical cancer patients, which can be beneficial for the patient, by giving mental support or underlining the seriousness of the disease, or negative, by further delaying the help seeking and diagnostic process.

8 Appendix

8.1 Ethical approval



	Addis Ababa University Medical Faculty Institutional Review Board	**SOP# AAUMF 008** **Version 2.0** **Effective date:** **1 Feb. 2009** **Page 194 of 13**
	Title: **3.2. Use of Study Assessment Form**	

ANNEX 3
Form AAUMF 03-008

IRB's Decision

Meeting No: 050/2013
Protocol number: 124/10/IM.
Date (D/M/Y): March 06/2013
Assigned No.………………

Protocol Title: Epidemiologic Survey of Ethiopian Urban and Rural areas on Breast Cancer and other Gynaecologic Cancer-Prevalence and Clinical Epidemiology		
Principal Investigators:	Dr. Matewos Assefa/Dr Adamu Addissie	
Institute:	AAU- MF Department of Internal Medicine	
Elements Reviewed (AAUMF 01-008) :	☑ Attached	☐ Not attached
Review of Revised Application ☐ Yes ☐ No	Date of Previous review:	
Decision of the meeting:	☑ **Approved** ☐ Approved with Recommendation	☐ Resubmission ☐ Disapproved

I. Elements approved-
1. Protocol Version No. ……………………………….
2. Protocol Version Date……………………………
3. Informed consent Version No. ……………………
4. Informed Consent Version Date ……………………

II. Obligations of the PI-
1. Should comply with the standard international & national scientific and ethical guidelines
2. All amendments and changes made in protocol and consent form needs IRB approval
3. The PI should report SAE within 10 days of the event
4. End of the study, including manuscripts and thesis works should be reported to the IRB

III. **TO ESTM** ☐

Institution Review Board (IRB) Approval: Period from **03/04/2013** **to** **December 2014**

Follow up report expected in
3 Months ___ 6 months ___ 9 months ___✓___ one year ___

Chairperson, IRB
Prof. Yeweyenhareg Feleke
Signature ___
Date: 03/04/13

Institutional Review Board Office (IRB) Faculty of Medicine

Associate Dean for Postgraduate and Research
Signature ____________
Date ______________

8.2 Consent form (English Version)

Patient number: ___________

Hello, my name is _______________________.

I am part of a group from Addis Ababa School of Public Health and the University Hospital Halle, Germany. We are trying to find out more about cancer diseases in Ethiopian women. Most common is cervical cancer. In order to find out more about perception and knowledge of cervical cancer we want to collect information from women who are suffering from cervical cancer from different parts of Ethiopia.

We ask you, if you are willing to be interviewed about your experiences with cervical cancer. We are interested to get to know your story in order to help other women in future. The interview will approximately take one hour.

The interview will be anonymous, thus whatever you tell us cannot be related to you in person. The interviews will be analysed and doctors from School of Public Health at Addis Ababa University and from University Hospital Halle will discuss the results.

We would be very happy if you could help us in this study.

Date_____________

Staff confirms that he/she informed patient about the study content and further proceeding:

____
(Signature of staff)

Patient agrees that he/she is willing to take part in the study: _______________
(Signature of patient)

8.3 Interview guideline

Objective:

- Gain knowledge about reasons for delay in treatment, perception and knowledge of cervical cancer.
- What could be changed within the health system in order to provide patients with cervical cancer an earlier treatment?
- What influences patients in their behaviour to look for help?
- Are their certain things which afflict the patients especially?

Key points:

- Initial symptom
- Person of trust
- When did they approach health system?
- Patient navigation system
    - Which care nodes?
    - Diagnosis
- Progress of disease
    - Other symptoms
- Restrictions in daily life
    - Work
    - Family relations
    - Financial matters
- Knowledge about cervical cancer
- Perception of disease
    - Why did they get it?
    - Treatment options
- Acceptance of disease by society
- Worries
- Acceptance of vaccination
        - Would you get your daughter vaccinated against cervical cancer?

- Socio-demographic facts
    - Age
    - Residence (rural/urban)
    - Ethnicity
    - Religion
    - Occupation
    - Marital status
    - Number sex partners
        - Did you have sexual intercourse with other men, besides your husband?
        - Do you think your husband ever had sexual intercourse with women other then you?
    - education
- reproductive history
    - number of children
    - age first child
    - abortion (spontaneous/ voluntary)
- contraceptive history
    - hormonal contraception
    - condoms

9 Selbstständigkeitserklärung

Hiermit versichere ich, dass ich die vorliegende Arbeit ohne unzulässige Hilfe Dritter oder die Benutzung anderer als angegebener Hilfsmittel angefertigt habe. Die aus anderen Quellen direkt oder indirekt übernommenen Gedanken, Daten und Konzepte sind unter Angabe der Autoren gekennzeichnet.

Ich versichere, dass ich für die inhaltliche Erstellung der vorliegenden Arbeit keine entgeltliche Hilfe in Anspruch genommen habe.

Hamburg, 10.09.2017

10 Erklärung über frühere Promotionsversuche

Weiterhin erkläre ich, dass ich die vorliegende Dissertationsschrift in keiner in- oder ausländischen Hochschule zur Promotion eingereicht habe.

Ich stelle den Antrag auf Eröffnung des Promotionsverfahrens erstmalig an die Medizinische Fakultät der Martin-Luther-Universität Halle-Wittenberg. Einen früheren Promotionsversuch meinerseits gab es nicht

Hamburg, 10.09.2017

11 Lebenslauf

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Ausbildung

Studium der Humanmedizin, Technische Universität Dresden (seit 2007)

- 3. Staatsexamen (befriedigend) 12/2015
- 2. Staatsexamen (befriedigend) 10/2014
- Physikum (befriedigend) 09/2009

Promotion, Martin-Luther-Universität Halle-Wittenberg und Addis Abeba University, Äthiopien (seit 2013)

- "From first symptom to treatment: a qualitative study of cervical cancer patients in Ethiopia"

Tropenmedizinischer Lehrgang, Universität Leipzig (02 – 03/ 2012)

Humanistisches Gymnasium Christianeum Hamburg (1997 – 2006)

- Abitur (Note: 1,8)

Clifton College, Bristol, Großbritannien (09/2003 – 07/2004)

- AS Levels: Alt Griechisch, Mathematik, Physik, Wirtschaft

Arbeitserfahrungen

Asklepios Klinik Wandsbek, Hamburg (seit 01.01.2017)

- Assistenzärztin, Geriatrie

Universitätsklinikum Eppendorf, Hamburg (06/2015 – 10/2016)

- Praktisches Jahr, Kardiologie und Nephrologie

Addis Ababa University Hospital, Äthiopien (03/2015 – 06/2015)

- Praktisches Jahr, Gynäkologie

Asklepios Klinik Altona, Hamburg (11/2014 – 03/2015)

- Praktisches Jahr, Viszeralchirurgie und Gefäßchirurgie

Laldagh Leprosy Service Center, Nepal (10 – 12/2011)

- Famulatur, Dermatologie

Vaemali Health Center, Vanuatu (07/2011)

- Hospitation, Primary Healthcare Center

Hôspital de Magenta, New Caledonia (04 – 05/2011)

- Famulatur, Pädiatrie

Patan Hospital, Nepal (02 – 03/2010)

- Famulatur, Geburtshilfe und Gynäkologie

Institut für Physiologie, Technische Universität Dresden (seit 10/2009)

- Studentische Hilfskraft

Praxis für Allgemeinmedizin R. Diederichs-Holthusen, Hamburg (03/2009)

- Hospitation

Helsesenter Øksfjord, Norwegen (08 – 09/2008)

- Hilfspflegetätigkeit, Demenzstation

Shangri-La Orphanage Home, Chapagaun, Nepal (02 – 08/2007)

- Volontär

Sykehuset Fredrikstad, Norwegen (10 – 12/2006)

- Pflegepraktikum, Orthopädie

Inter Cris Messeagentur (seit 2007)

- Internationale Hostess, Norwegisch

Obdachlosenhilfe Alimaus, Hamburg (03 – 06/2003)

- Sozialpraktikum

Apotheke Nienstedten, Hamburg (2002 – 2006)

- Fahrradkurier

Engagement

- Teilnahme UN Climate Change Conference, Bonn (2011)
- Ehrenamtliche Mitarbeit bei der Entwicklungshilfe Govinda e.V. (seit 2007)
- Delegierte Model United Nations (2005; 2006) und Model Europa Parlament (2002)
- Schulsprecherin (2004 – 2005)

Sonstiges

- Interessen: Sport (Radfahren, Tennis, Kickern), Lesen
- Sprachen: Englisch, Französisch, Norwegisch, Amharisch, Nepali