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The Life Event of being Diagnosed with Cancer in Midlife

How to Increase Individual Value seen from a Patient
Perspective

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ABSTRACT

The numbers of diagnosed cancer patients have increased over the past years, and are still increasing. This is because of increased survival rate due to better medical treatments, which enables people to survive and grow older with a cancer diagnosis. The public healthcare system today uses standardized production methods; standardized systems that are supposedly used in order to handle normal distributed variation. In the public sector there is no normal distributed data, but rather a large incoming variation into the system. The incoming patients are originally from different backgrounds and have different life situations, and expectations.

The idea of a "life situation" has now become a central point of awareness for future healthcare process design, and the fact that the patients should be seen as a resource to the process. As of today, the patients are an unused resource not included in the design nor the production of the actions delivered by the different system actors. In this study, the willingness and the importance of including the patients in the design of their own treatments are further analyzed. Also, the importance of seeing the different processes offered by the actors as services is vital, in order to make the system more flexible and adaptable to the individual patient. The patients are the ones, who will consume the services, and they are able to express their needs, and by including them the patients and the system will benefit. Today, the different processes could be seen as fragmented and divided. The public sector is not seen as one working unit, but instead many different actors and processes with many different goals and strategies.

Concluding, the entire system of all actors included in the healthcare treatment process of cancer patients would benefit from changing the focus from their own actions and the results they produce, to focus on the patients. The actual life event of the individual patient needs to be considered when diagnosing the patient, in order to help find solutions to the life outside the hospital. The actors could start cooperating, and decrease the distance between their organizations in order to establish sustainable communication and shared goals.

Key words: life event, individual patient value, healthcare, cancer, midlife, silo organizations, public sector, interaction between authorities, variation, expectations

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Gothenburg, 2015-05-08

GLOSSARY

| | |
|-------------------------------------|--------------------------------------------------------------------------------------------------------------------|
| Applying for work (AFW) | A state where an individual is searching for a job and gets financial compensation funded by the state. |
| Fatigue syndrome | Long debilitating fatigue and feeling of exhaustion. |
| Medical cured | A state where there is no longer any sick physical parts within your body. |
| Officers | A title of the person whose task is to handle all incoming cases to Försäkringskassan. |
| Patient | A person who is under medical assessment or treatment in the health care. |
| Preventive sickness allowance (PSA) | A method enabling work when a patient feels strong and gets financial compensation when not strong enough to work. |
| Return to work (RTW) | The state when a person is able to return to a workplace. |
| Sickness allowance (SA) | The economic compensation funded by the state that a person receives during a period of sickness in life. |
| User | The customer at Försäkringskassan. |
| The system | The word used when The Healthcare Organization and Försäkringskassan are expressed as one unit. |

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1. INTRODUCTION

This chapter provides a background of the event of getting diagnosed with cancer, and the actors and processes that a cancer patient has to deal with. The purpose of the thesis is then presented, along with the problem analysis and the research questions.

1.1 BACKGROUND

To get diagnosed with cancer changes the life situation not only for the patient, but also family, friends, and everyone in the surrounding. The questions are many and the anxiety and uncertainty of living in unawareness of what the future holds is terrifying and hard to accept. Besides daily fights of handling feelings, mental challenges and treatments in the hospital, there are practical issues that have to be solved outside the hospital. These patients are adults in the middle of life, and have to pay bills, work, and maybe also care for a family. Children in school, a worrying partner, and all the daily routines have just been swept away. Even though the surrounding people understand the situation there are still many things to handle. The normal life outside the hospital is suddenly put on pause, but the rest of society has expectations that are hard to avoid.

Sweden as a country has a social safety net that is supposed to handle and support a person that is going through a life crisis or a disease. Försäkringskassan, the public insurance company funded by taxes, primarily provides economical help for people that cannot work, and work in cooperation with Arbetsförmedlingen for people waiting to find jobs. It also provides economic aid to people with special disabilities, and distributes child support. The authority does also act as a bridge between employers and employees, and is meant to facilitate both parts' situation in which an event affects a person's ability to work.

(Försäkringskassan, 2012) The health care in Sweden is basically funded by the state and exists at three levels; national, regional and local. There is not unusual with long waiting times for patients, except from emergency cases, depending on the disease and area for the patient. The patient is paying a nominal fee for examination but for longer treatment there is no charge at all. (Swedish institute, 2013)

In 2009, a national strategy for cancer was written, which focus on the future needs and challenges in order to improve and ensure the quality of care and handling in Oncology. The patient perspective would be especially noted where actual experiences and perceptions would provide a platform and basis for improvement. The strategy also aims to prolong survival time and provide an improved quality of life for individuals who live or have lived with cancer. This is by striving to make healthcare more equitable, more efficient and more knowledge-based. The aim is mainly to see cancer from a holistic perspective where the whole community is involved and how it affects a patient's journey. (SOU 2009:11)

Regionalt Cancercentrum väst, referred to as RCC, is an organization that works to maintain a high quality of cancer treatments, and to improve cancer care in primarily the west regions of Sweden. It does also work actively to bring together various stakeholders such as patient organizations, government agencies, politicians, officials and researchers to continually streamline and bring health care forward. (Allander, 2012)

The year of 2012, the number of persons that received a diagnosis of cancer was 54447, and the different kinds of cancer are illustrated in the Figure 1.1 below. Although the percentage of surviving cancer is increasing, the disease is the most common cause of death for people under 85 years. Over the past 20 years the number of cancer cases increased by 2.1% for men and 1.6% for women. One factor contributing to the increase in population is growing as well

as a longer lifetime for humans and thereby also increasing the risk of having a cancer tumor. (Cancerfonden, 2013)

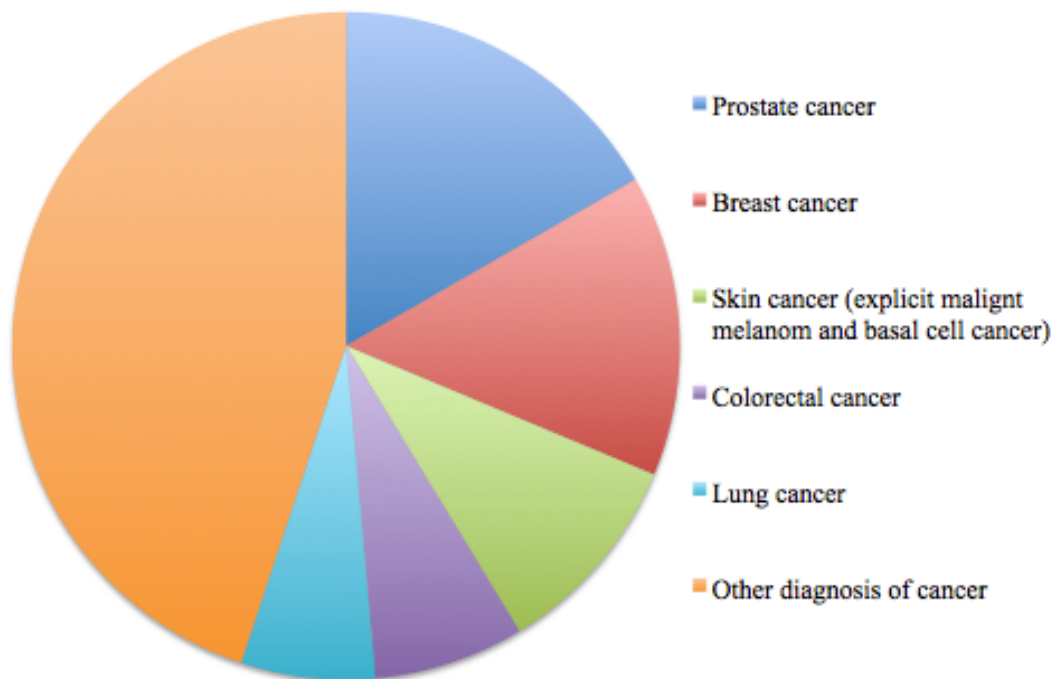


Figure 1.1 illustrates the percentages of the five most common cancer diagnosis in Sweden 2011 (Cancerfonden, 2013).

The risk of getting cancer before an age of 65 is about 30 percent for men and 40 percent for women. The percentage of women is higher because it is more common to have gynecological and breast cancers earlier in life than the equivalent of the men's most common form of cancer prostate as illustrated above. (Cancerfonden, 2013) In the Figure 1.2 below is the overall survival rate for a five-year period and a ten-year period, for both women and men.

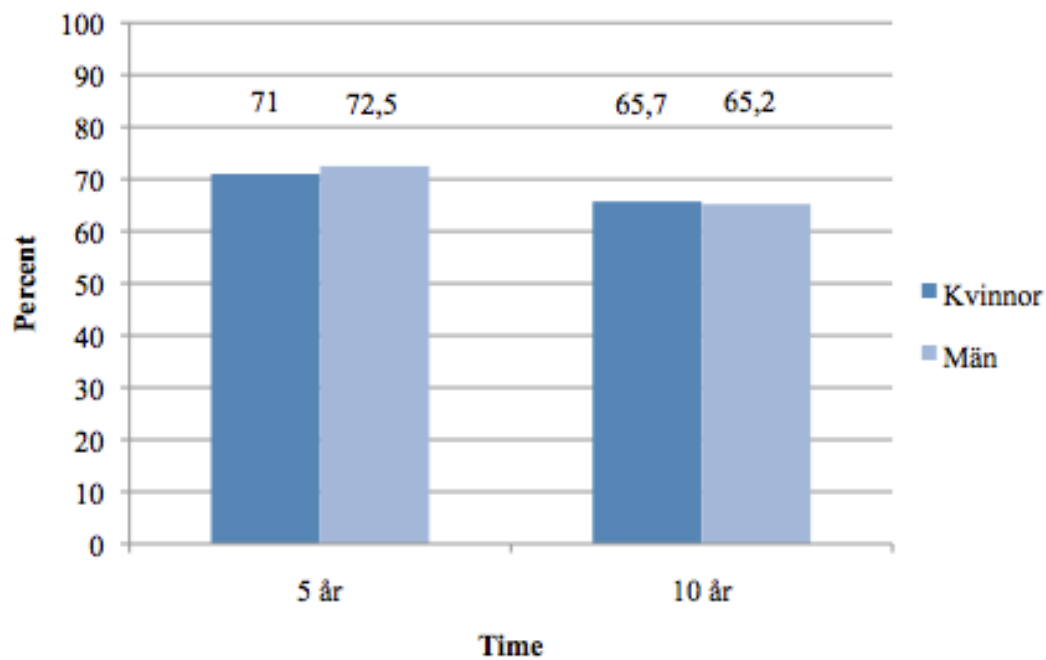


Figure 1.2 illustrates the estimated 5-year respective 10- year survival rate for patients receiving a cancer diagnosis. The results show data from the years 2009 to 2011 (Cancerfonden, 2013).

As seen in the figure there will be consequences for people in the surrounding of a cancer patient, due to the survival rates. The concept of "Life events" is something that has come to have a greater focus in the public sector. A life event is the overall situation from a national perspective that occurs when something abnormal happens to an individual person. For a life event count all actors that may affect the individual person, and the time span when the person is expected to be active or to have consequences of an event. A life event is thus to zoom out from the incoherent systems, and the fragmented processes the might public sector consist of, in order to get an overall picture of the events and achieve synergies and improvements of a common mindset. (Quist, 2014)

1.2 PURPOSE

The purpose of the study is to get a deeper insight of how we can create individual value for patients according to their different life situation when getting cancer in midlife. The aim is to, from a patient perspective, identify areas, which are in need of improvement when going through the life event of being diagnosed with cancer. Focus is to understand in how government agencies and health care through collaboration can create knowledge exchange and shared processes to achieve a higher perceived quality and easier life situation for the patient.

1.3 PROBLEM ANALYSIS AND RESEARCH QUESTIONS

In year 2020 it is predicted that every second person will at some point during his or her life falling ill. (Conradi, 2014) Even if the number of patient diagnosed with cancer will rise, so will also the number of people that survive the disease. This increase is a result of research and new tools for early detection of cancer and new effective treatment methods. (SOU 2009: 11) One direct effect of the rising number is that the public system will be pushed further and handle even more people than today. More people also have to make the journey from getting

a cancer diagnosis to live and deal with the aftermath of the disease. In Västra Götaland and Halland are today X persons registered on sick leave for psychiatric disorders due to a previous tumor diagnosis. (Försäkringskassan, 2014)

When a patient is diagnosed with cancer and enters the public organization system few things are today automatically performed. The interaction between authorities is unclear and the process times are often long. Uncertainty arises regarding what the patients should do and how life will correlate with the upcoming treatment process. (Dower, 2012) The healthcare organization and the Försäkringskassan are two of all organizations, authorities, and people that a patient has to contact when being diagnosed, living with, or recover from cancer, and even more people are affected as illustrated in the Figure 1.3 below. Often the processes from public sector are separated and fragmented with a standardized way of working, which allows low grade of flexibility for meeting individual needs. The different departments are also divided into silos with little cooperation between the organizations. This makes it hard to get a solid knowledge of the expected journey that a patient will face (Quist, 2014).

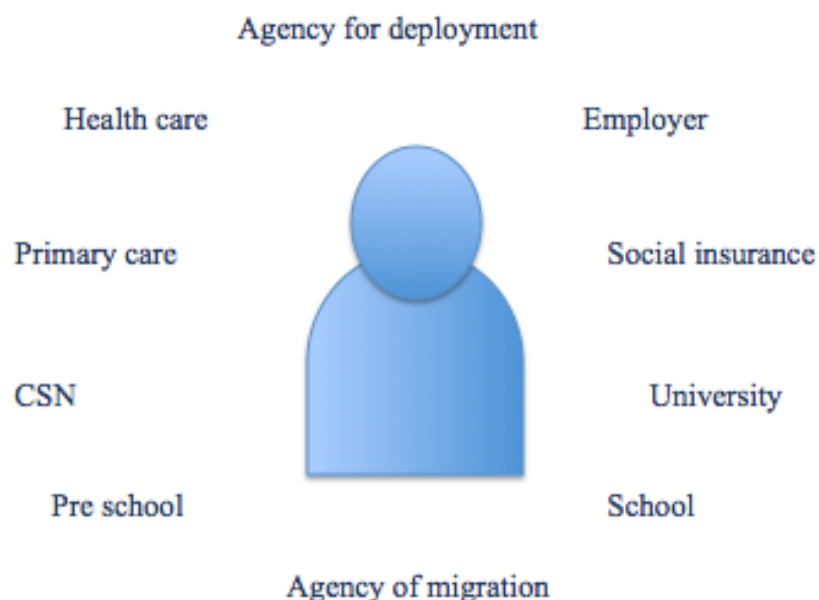


Figure 1.3 illustrates parties that might be involved sometime with a person when being diagnosed with cancer.

Many tools and methods currently applied to the public sector is not really designed to work in industries where production takes place behind closed doors and where the process thinking, efficiency and standardization of an operation is applied to physical goods. The item is distributed through the channels and consumed by the customer, where the value virtually gets destroyed. What has not always been fully into account is that civic meeting drives the public sector where value is created by the interaction of people and where the value is gradually built up. The value is not consumed but reused and converted repeatedly. It is impossible to ignore the defective goods, which can be thrown away if they do not fit inside standard frames, or to simply see the process as a distribution channel. Working with people and services, we need to think differently and this has not always been done. (Quist, 2014)

The public system of today is not fully created for handle individuals that are in the middle of life. During EUMASS Congress in Stockholm George L Delclos criticized the assumption that sickness leave in general often assumed to be normally distributed. This is often not the case at all, but rather that the cases of sickness leave have a great variety and spread outside the intended range. (The Scientific Committee of EUMASS, 2014) Individuals in midlife have a great spread of life situations. Family structure, work, economic situation, physical and psychological health are just a few of all parameters that can vary from patient to patient. To only offer standardized solutions at the system level that cannot handle this variability complicates the patient's life situation.

Patients are an almost unused resource, and as of today their experiences often are gathered through surveys and focus groups. However, it is rare that patients actively contribute to the offensive business development. This may seem a little strange when the patients are actually the only ones who have the holistic picture of an experience. (Andersson, 2011) According to WHO, (2000) in Häger and Anell (2012) the overall impression of Swedish healthcare is low due to weaker responsiveness to patients' wishes than other countries participating. The unclear process could in a negative way affect the good parts of the treatment process of a cancer patient, and the perceived quality could be considered lower than what it actually should. The health care and public agencies are not the only area who are working with collecting and take experiences in consideration for further improvement of the business. The justice system has for several years faced the same problem. Lindgren and Qvarnström (2003) emphasize the importance of collecting victims' experiences and views in order to promote and create tighter interactions between instances and find areas for possible improvement.

In the recent year, various platforms have been created to facilitate an increased collaboration between healthcare, and agencies in the public sector. In the western region RCC has in 2013 and 2014 created dialogue days and interaction sessions to begin to build networks and establish important links between cancer care, Försäkringskassan, CSN, and Arbetsförmedlingen. To open for discussion and listen to patients' experiences is one step in right direction for the ability to together take responsibility and ensure that no patient falls through the cracks during their journey. It is also an important step towards a more cohesive safety net. (Allander, 2014) The problem lies in the need for resources; someone who is responsible for and how things actually are put into action and that all are willing to work for a change in same directions.

Research questions

- How can the problems perceived by a patient in the cancer care and public sector be decreased?
- How do we create individual value?
- How can the system offer individual treatment for patients, while still having standardized systems?

1.4 DELIMITATIONS

The study will cover adults between 30-60 years old, also referred to as *midlife*. These people have a complicated situation with interruption from work and University. The absence from work also can give a negative economic impact, which can result in large consequences for the life situation. These people often have children who need to be taken care of and supported. The study will cover a research of Försäkringskassan and the Healthcare

organization. These organizations are the two largest the patients have the most contact and interaction with during and after a cancer diagnosis.

The research has a patient perspective and the recommendations are based on solutions prioritizing the patient's value first. This means that no investments calculations or further analysis will be done of the possibilities or risk that the recommendations will lead to for the organizations involved. Neither will details descriptions of how the suggested activities will look like for enable an implementation be examined. The geographic regions that have been studied are Skåne, Västra Götaland and Halland.

2. THEORETICAL FRAMEWORK

Identified in the problem analysis, this chapter begins with an illustration of the current system situation regarding the life event of getting diagnosed with cancer. The Figure 2.1 below illustrates the problem areas identified in the problem analysis, regarding the interaction between the patient, the healthcare organization, and the Försäkringskassan.

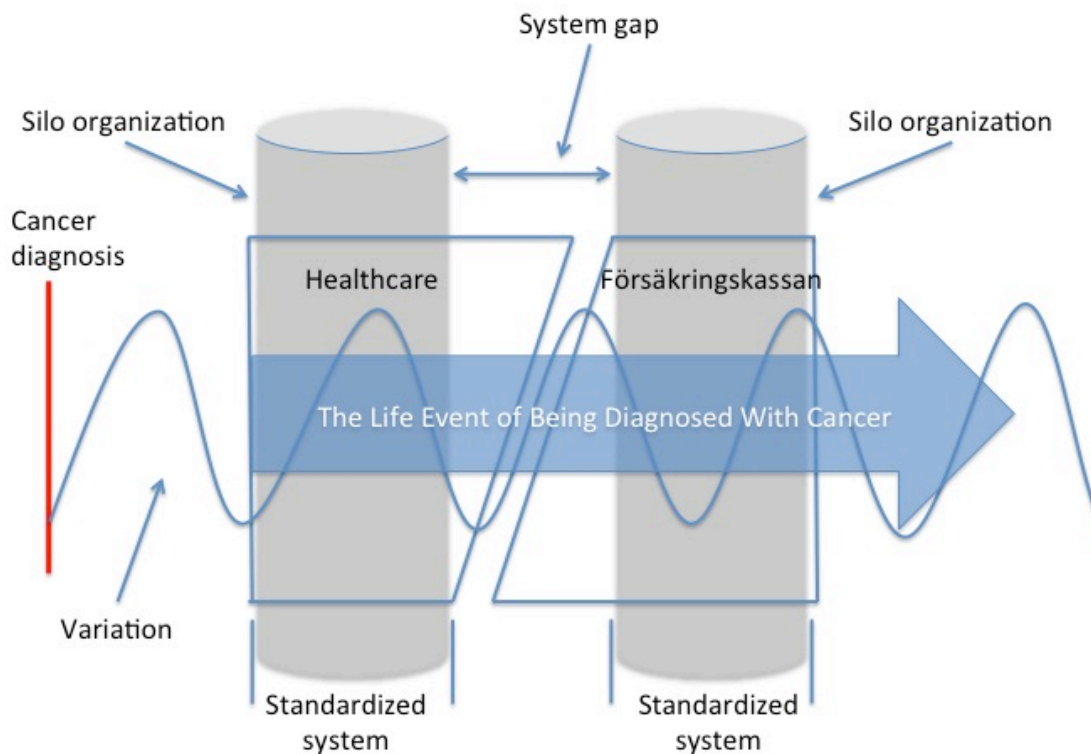


Figure 2.1 illustrates the system and the process of the life event of getting diagnosed with cancer.

In the Figure 2.1 the red line illustrated the point in time when a patient receives a cancer diagnosis. From this point there is a variation in the behavior and need of all patients, illustrated by the blue sinus curve. The life event of a cancer patient starts when entering the caring process, and as of today it is the first meeting with the healthcare silo organization. The actions and activities within the healthcare organization are mostly separated from those in the next silo organization, the Försäkringskassan. They somewhat overlap but they have their standardized and separated systems, and therefore they do not cooperate any further. When the patient is through the treatment process the variation in the behavior and needs continue, but the care from the system stops.

The following theoretical framework will be build around the illustration of the different problem areas of the current system process. As the life event of getting cancer is the overall focus, illustrated as the blue arrow, the chapter will begin to describe further what a life event is, and how it can affect life. In order to see it as a life event, and in order to see the entire system as a whole, the system will be seen as a value creating service system, and this theory will also be further explained in the next section. Then system gaps, and theory regarding silo organizations with standardized ways of working will be described. The incoming variation to the system will be described from a theoretical view.

2.1 LIFE EVENTS

A life-event is defined in the Oxford Dictionary of Sociology (2009) as eliminated changes in terms of employment, education, or health at a particular point in a person's life. Different life-events are interrelated and can be analyzed in terms of how they affect each other. A major illness is defined as a largely affecting life-event, which causes turning points in a person's life in terms of social life, spare time activities, and work, but it can also affect a person's values and attitudes. (Oxford Dictionary of Sociology, 2009)

When being diagnosed with cancer the entire world gets up side down and it is hard to think about anything else than the diagnosis, in the morning and throughout the day. It affects not only the patient and the body, but family, friends, and the ability to work and function as before. Lots of feelings and questions are raising, and the cancer will force life to change and to adapt to the new situation. It can also be hard to listen, talk, and remember during the time of fighting the cancer, because the unconscious might keep leading back to the cancer diagnosis. Cancer is different to all people, and the result of how they receive it differs. The beliefs and values of one person differ from all other patients, and that will form the cancer diagnosis and the content of getting cancer, and will mean something special to the individual person. The cancer demands are high and the patient with its surrounding needs to adapt to the new challenges. A person can never be prepared or expect to get a diagnosis like cancer, and this is why many unexpected events will be faced throughout the cancer journey, and all patients will have different experiences. Shock, fear, guilt and anger are just few of the varying feelings that might come up along the way. All of these varying factors will affect the life outside the cancer diagnosis individually for every patient. (American Cancer Society, 2014)

2.1.1 VALUE CREATING SERVICES

A service consists of several components. Unlike physical products a service does not necessarily contain physical components, but rather a number of combined processes, skills, people, and materials. When designing a service the main challenge is to focus all different

components towards the same final goal: customer needs. (Meyer Goldstein et.al, 2002) A service is produced and consumed simultaneously, and this is usually referred to as intangibility. (Morelli, 2009) The service can therefore be seen as one package, or as a sum of different components for both the service provider and the customer. When the service is offered as a package the customer will receive and consume the already pre-designed service as it is. If the service instead is a sum of components the customer can be involved in the creation of the different components and help designing and customizing the service while consuming it. It is of outmost importance that the expectations of the service provider and the customer coincide, in order to satisfy the customer. Therefore the nature of the service needs to be understood and the final picture of the service needs to be clear and shared, in order to be able to design the service in the most suitable way. (Meyer Goldstein et.al, 2002)

One of the models highlighting the most important components in value creating services is the SERVQUAL model developed in 1988, as the Figure 2.2 below illustrates. The black arrows in the upper part of the model illustrate what factors that affect what the consumer expects to get out from the service. The word of mouth, personal needs, and past experiences all affect the final expectations of the consumer. Then the consumer perceives the service in the perceived service box, and the previous expectations affect the satisfaction of the consumer. The black arrow to the right in the lower part of the picture, illustrates how the management creating the services and designing them has understood the needs, and has communicated back to the consumers what they can expect. The other black arrow pointing from service delivery to the perceived service illustrates what the consumer actually gets in the end.

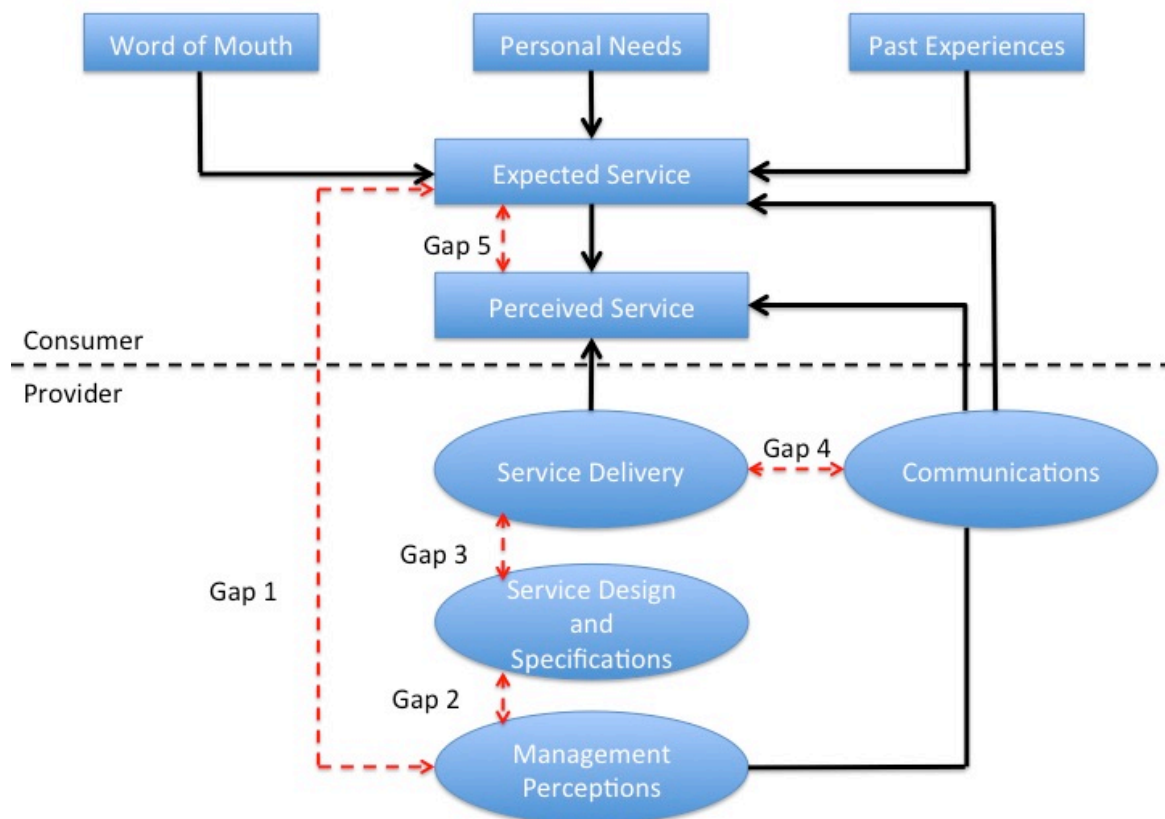


Figure 2.2 illustrates the SERVQUAL model illustrating the most important components of creating high quality services (Arlen, 2008)

The model wants to highlight five factors of service quality and those are reliability, assurance, tangibles, empathy, and responsiveness, in the relationship between the consumer and the service provider. If the perceived delivery is larger than what the customer expected, the service quality is experienced as high. In the picture, there are red dashed arrows illustrating where "gaps" can occur in the system. The phenomena of gaps will be further explained in the next session, but in the SERVQUAL model five specific gaps are identified. (Buttle, 1996) The first gap occurs if the management providing the service has not fully understood the need of the consumer, but instead provide them with services they do not want. This problem can occur if the service producer has not completed a market research, analyzed the consumer information poorly, or if research has not been focusing on the demand of the consumers. The second gap exists if the service design and specifications are wrongly designed, even though management might have had the correct interpretations of what the consumer really wants. This gap can occur if the planning procedures are poorly developed, and if the management is not fully committed. Between the service design and the service delivery can a third gap occur, due to lack of education or commitment by the personnel performing the service. The fourth gap is between the service delivery and the communication channel. The consumer is very open to advertising and what a service provider promises, and if the communication is poor or promises the wrong things, the consumers' expectations will not be met. The fifth and last gap occurs if the consumers' service expectations and the perceived service do not match. (Abu-El Samen et al, 2013)

The customer-oriented view of services is becoming more relevant since the value of the provided service can be increased through customization. The customers therefore need to be involved in the value creating operations instead of just consuming it afterwards. (Johnston, 2005) Customers are becoming more globalized and more efficient, while the individual needs and demands are highly related to culture, social and economic conditions. In order for organizations to be able to meet the needs and wants of their customers they need to differentiate themselves and start focusing on how to customize their propositions. Many years ago, before the industrialization people were producers, they managed their own everyday functions and needs such as washing of clothes, taking care of children and production of their own food. As of today, we have instead moved on to become consumers of products and services, where we have machines washing our clothes, daycare personnel taking care of our children, and grocery stores providing us with food. This has made us into passive consumers, with rising expectations and demands every day. Satisfying all of these needs requires plentiful resources even though the consumer in terms of effort, participation and skills requests little. This situation is becoming unbearable. In order for an organization to handle the fragmented customer needs, involvement of the customers in the production of services is needed. (Morelli, 2009)

Organizations need to refocus and consider themselves as value creating organizations, where the customer no longer portrays as the end goal of the process, but rather a co-producer in the value creating process. This affects the organizations since they no longer can keep the customers as their main focus, but rather as help and an asset in the production process. This is an interaction between people, needs, and the ability to create, and it is therefore important for the organization to accommodate its process so that customers can be fully involved. It is important to identify the roles of the involved actors and participants, and the rules that should be applied. Clear directions and written agreements stating who provides the service, who consumes and can access the service, and what is required from the involved participants in the process are necessary. In the case of co-production, the ability to set boundaries is of great

importance. Especially in order to establish within which field of expertise each individual participant holds the most responsibility. (Morelli, 2009)

The involved actors are part of the design process of the service and they are required, and also responsible for finding the best design solutions possible in order to fit the situation. Therefore it is of highest importance that all people involved are supplied with all the information and knowledge necessary, in order to create the most suitable solutions. Furthermore, they need to access relevant communication strategies in order to get help and input from everyone involved. The participants are of different backgrounds and therefore the system needs to provide each and every one of them with the most individually suitable information and communication strategy, in order to get the best possible output. (Morelli, 2009)

2.1.2 SYSTEM GAPS

There will always be some people "disappearing" in a public sector process, because their individual needs are not met, due to system gaps as illustrated in the Figure 2.3 below. The public sector system needs to understand why the disappearing occurs, and know how to replace the void with valuable content. Many organizations have top-down management, which results in difficulties when trying to get organizations to work together. It is therefore hard for them to agree and work in the same direction. It is hard to link different services together in order to care for individual human needs. The spread within the services will counteract the creation of complete value of the process as a whole. The public sector system consists of many different organizations with the overall purpose to care for people. However, several reports have shown that people with special individual needs are falling out of the system, since the system is not equipped to take care of those certain individuals. The individuals possess the risk to get stuck in between different organizations due to lack of communication, information and knowledge regarding the responsibility distribution among the different organizations. This results in poor service such as insufficient information sharing, bad timing or late medical help for the individual in need. The gist of the public sector system is to create value for the individual person and caring for the individual's needs. A nurse getting water for a patient, a doctor talking to relatives, an officer at the Insurance Fund helping an individual with financial advice, these are distinctive examples of value creation in the public sector system. (Tyrstrup, 2014)

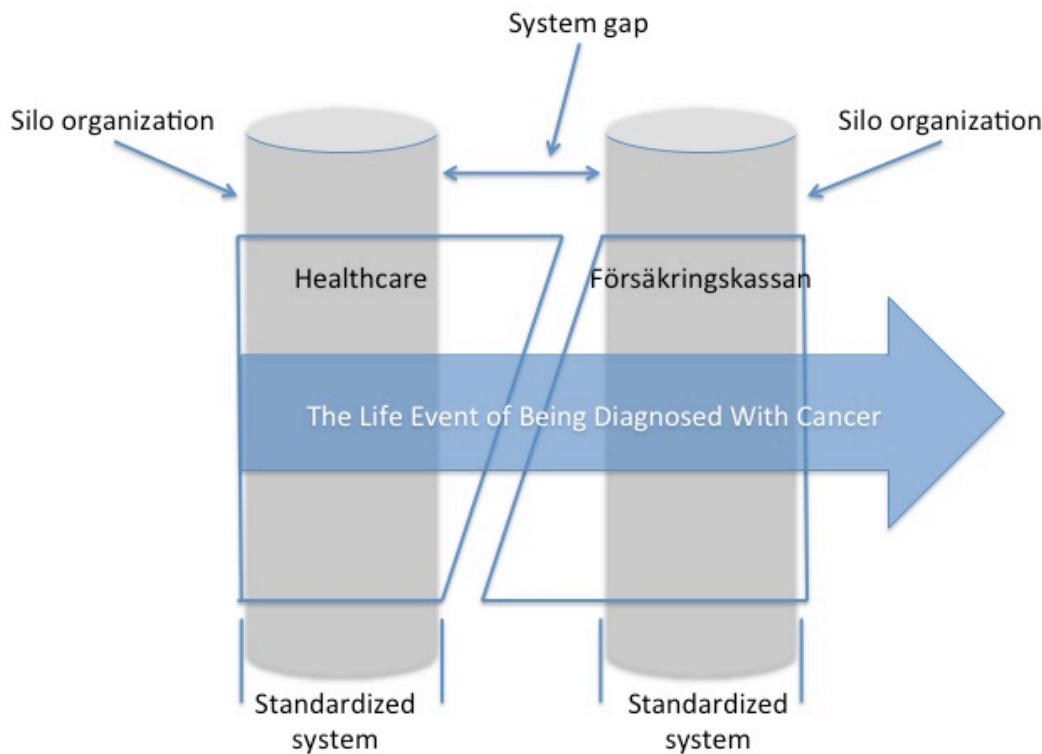


Figure 2.3 illustrates the system gap that exists in the caring process of a cancer patient.

However, many times the demand of services from different organizations within the public sector system is needed and that requires different professions and specialists to cooperate and work towards a common goal. They need to synchronize their activities and specialized knowledge within different areas of expertise, in order to solve and create value in the more complex situations. In today's public sector system this is very hard to establish due to some important circumstances. The organizations within the public sector system are often thought of as very big, and they choose to manage their organizations in that way. Therefore there are long lead times in processes and the systems are very complex within the organizations. Furthermore, the roles and responsibilities of the involved organizations possess an uncertainty regarding workload and functions among themselves. Although the end goal is the same for the organizations, high value for each individual, it is difficult to obtain because of the unclear distribution of tasks among the organizations. The individuals who do not fit the design of the public sector system are said to fall out of the systems, or into gaps of the system. These gaps occur when the cooperation within an organization, or between several, is absent or fail to function. The system therefore fails to meet the needs and demands of the individuals. Many researchers claim it is time for a change in the perspective and view of the public sector system and the involved actors. The aforementioned gaps display the possibilities for renewing and developing the system in terms of value creation, organizational management, and evaluation. (Tyrstrup, 2014)

Cooperation between different organizations creates value, and more importantly, in the public sector system, the cooperation between people creates value. Meetings, communication, information and activities involving people create value through an efficient and safe process. When the perspective of value is changed from the public sector system to the individual person, a holistic view of the process will be at hand. Instead of only seeing the ongoing processes within the public sector system the individual person can express the situation and give a holistic view of his/her life situation. This holistic view, from an

individual perspective, characterizes the entire process. However, today there are many holistic perspectives colliding in the processes of the public sector system. Most actions within the public sector system are part of the holistic view of the individual. In the perspective of a patient all actions counts and they need to cooperate with each other, but also synchronize and perform at the right time. The work needed in order to demonstrate the holistic view of a patient, will be divided between the different actors, as well as the responsibility. An increase in specialization will give a higher grade of efficiency and productivity in the creation of individual value. (Tyrstrup, 2014) Morelli (2009) says it is time for the organizations to start engaging the individual person in the process of creating value, and therefore there is a need of changing the process perspective of the organizations. The change will involve going from producing valuable goods a person later on can consume, to co-producing individual value together with the person and therefore see it is a service. (Morelli, 2009)

2.1.3 SILO ORGANIZATIONS

Silos in public sector organizations are the different and separated departments or divisions within the organizations lacking in the cooperation with each other, as illustrated in the Figure 2.3 above. There are many critics of this separate category thinking, excluding the facts that many customers are staying for a long time bringing new customers into the system. There is however a major challenge for organizations to coordinate and get an interaction between different departments. (MacStravic, 2007) The system of today faces large integration challenges and there are strong incentives in developing answers and solutions. There are many opportunities to gain from integration improvements since high-value services can be provided in order to care for the customers during their entire stay in the system, and their life situations. The focus needs to change from silo thinking to strive for cross-boundaries and cross-departments. The organizations need to be prepared and aligned for this new environment of cooperation and work across the silo borders, which Mohler refers to as "seamless" work cooperation (2013, p.36). Evidence-based research has shown positive results when organizations have broken down their silo structures and reached a high level of integration. The results have shown increased individual value and access for the customers, and therefore also increased customer loyalty. (Mohler, 2013)

Integration developments and improvements require analysis, understanding, and agreements of relationships between different functions, both interrelated and interdependent. These relationships are then to be aligned with processes, networks, procedures, and requirements. Integration in public sector organizations is the cooperation across functions and activities in order to deliver as high-quality and high-values services as possible to the customers. An important factor to consider when integrating different functions and activities in a public sector organization is the shared aim of the integration. (Mohler, 2013) According to Mohler this aim can be divided into three parts: leadership, cultural change, future state. Where the results should be shared goals and culture, and that all actors involved take their individual responsibility (2013).

2.1.4 STANDARDIZATION

In the public sector organizations of today, the goal set by the inspecting instances is to standardize work, in order to improve efficiency, and this is illustrated in the Figure 2.3 above. This is basically based on the understandings of a production process producing physical products. The three key factors in public sector organizations are: efficiency, uniform

and legal security. They are all in the value description of many public sector organizations and act as guidelines in their work, and standardization is the way of conducting uniformity in the system. (Quist and Fransson, 2014) Work standardization aims towards uniform the processes within the organizations and can involve technical processes, equipment, administrative work, operation procedures, and quality measurements and requirements. It also includes the design of processes. First the method describing how the work is to be conducted is standardized, and then the timetable is standardized based on the chosen method.

The main advantages to gain from standardized work are decreased costs, increased productivity and efficiency, improved quality, and a more efficient way of developing new skills among the employees. It is conducted by eliminating unnecessary operations and merging some operations, if possible, in order to decrease the number of operations needed. This is only possible if all operations are evaluated and clearly defined, which usually results in process improvements. The improvements are often established by dissolving large processes into smaller sub-processes, and from that perspective eliminated or merged into clustered operations. Standardized work will be able to manage standardized operations, but if outliers or special needs arise, there could be difficulties handling them. The standardized work will have to be reinterpreted or redesigned, in order to meet the outliers, or have back-up processes handling the special cases. (Ullman, 2014)

2.1.5 FLEXIBILITY WITHIN STANDARDIZED SYSTEMS

Flexibility is about the ability and intention to change and adapt to new ideas and circumstances. Flexibility enables quick response, and to meet challenges early and efficient. It does also open up for cooperation and integration, as the previous section requires. (Lagarde, 2014) Flexibility is needed in order to create customized services. At the same time it needs to be managed within the framework of standardization, since rules, regulations, since the need for efficiency applies. This is a new concept and it is referred to as a standardized flexibility. The public sector has experienced an increase need of individualized services, and it is therefore a matter of balancing flexibility and standardization. This can be conducted by having flexible solutions and individualization, while following the rules and the set standards, and ensuring the equality of treatment in order to legally secure the system and make it efficient. (Røhnebæk, 2013) Standardization can help creating flexibility by opening up new possibilities and combinations of services outside the scope of what the system earlier thought was possible. Since the standards are pre-determined it could encourage new flexible and innovative solutions more easily than if someone was to develop it from scratch, without any pre-determined specifications. However, standardization is also said to hinder flexibility in terms of rules and regulations. (Egyedi, 2001)

Due to increased customer demands services today need to be adaptable, extendable, and flexible. There are always upcoming changes to care for, and to meet new demands and needs the system needs to be flexible. If a standardized system involves different actors, or many different subsystems or components, the need for flexibility is high due to changes in one part of the system might need changes in the other parts as well. The degree of flexibility can be focusing on the entire process in order to get system flexibility, or focusing directly on some of the parts where flexibility is needed the most. To choose the most suitable strategy can help building up a flexible system in the long run. There is also a matter of the content of the different parts in the system, whether or not they should know about each other's content. The different parts can be developed separately by the different actors, or in cooperation. Depending on what the system requires making the different parts independent can increase

the degree of flexibility. This does require a standardized interface in the connection between the different parts of the system, in order to get them to fit together. (Hanseth et al, 1996) In the situation of public sector they need to strive for engaging in the interface between the different actors, and to involve each other earlier in the process of creating individual value. (Røhnebæk, 2013) In order to do so, the organizations need to rethink and design a system where cooperation can be established. This will require organizational challenges and a need for change, because shared purposes, culture, and environment are less flexible due to governmental rules, regulations, and differences in interests. (Ostroff, 2006)

2.1.6 VARIATION

The amplitude of variation demands a clear focus for lucidity. Variation is everywhere and affects everything. The need for awareness of variation is necessary in order to decrease the affects of it. (Hall and Hallgrimsson, 2005) High variation in processes results in lower reliability level and a higher level of uncertainty in the output of the processes. The importance of a process's level of design is truly notable when there is a wide variation in the input. There is not only variation in the input, but also in the environment where the process operates. Challenges will have to be tested and understood in order to design a process suitable for the given variation. In a production process of physical products components failing the tests can be excluded and replaced by more suitable components for the process. The production processes will be tested and changed in order to increase the reliability of the process by using more efficient ways of handling uncertainties and variation. New ones can replace parts and components in order to lower the levels of affection caused by variation. (Cheng, 2006)

However, in a service process variation is even more unpredictable, compared to a production process of physical products. It is difficult to determine what causes the variation, and what effects the variation has on quality of the process and the output of the process. If any clear indications are found pointing at different sources of variation the process owners need to decide how to face the challenges through process design, in order to decrease the effects of the variation on the output of the process. In public sector organizations the government makes decisions aiming towards decreased effects of the outputs. The public sector organizations do it as well, which results in many decisions leaning towards the same goal in the end, but with different individual goals on the way there. This can cause irritation and confusion in the process. High authorities in order for the different public organizations to follow set rules and regulations, but that means the organizations have different laws and regulations to follow depending on where in the process they are located. There is also a variation depending on where in the country the different organizations are located, or where their sub-organizations are. In the case of location, different states have different advantages and disadvantages. There are some differences in the financing and regulations, and in the tax reduction system. There are also differences in the wages and payments among the involved actors, which causes variation in the way people are interested and engaged in their work. This causes variation in the way of treating and meeting people in the public sector processes. (Newhouse et.al, 2013)

There is eagerness in the public sector organizations to find standardized and universal solutions and designs to everything, in order to make processes more efficient. They want researchers to find the "answer" to this question. Is there a best color, a best suited shape of a room? Is there one best size of a toilet, a most efficient design of a process? They are trapped in the thoughts of universal and standardized solutions. Public sector organizations search for

answers to their problems and challenges with variation, because of the great variation in service processes. The suggested process designs are tested and evaluated, but whether the chosen process design is the correct and most efficient one is hard to completely determine, since there is always a way of improving it even further. The solutions and answers to the challenges will always have to be tested in the environment of the variation. In the decision of process design there are many parameters of variation affecting the process itself and its output. There are many different sources of variation such as geographical location, culture, the financial possibilities and regulations of the state, and regional differences. (Hamilton, 2014)

All of these sources of variation result in challenges for the designers of the processes, where the variation is to be handled. The designers, the public sector organizations, need to understand the sources of variation and work with them actively. Every process needs to be seen as a unique situation and be handled differently, thus keeping from applying a standardized design as a first option only because it is how it used to be managed. This is especially important when processes interact or cooperate with other processes. Most designers and people working with process variation designs think that every process is unique and needs to be managed that way. However, in most cases they end up using an already existing design or model previously used in a similar project that was really successful, because of uncertainties in the way of acting. (Schapira, 2013) The design is being applied even though the new process has totally different sources of variation. In today's society and public sector organizations variation in situations, conditions, contexts globally and regionally needs to be understood and handled in the most suitable ways in order to decrease the effects of variation, difference and uncertainties. (Hamilton, 2014)

2.1.7 UNCERTAINTY

Uncertainty can completely block the mind of a person and can be trigger and increased by many unknown and unexpected events, especially when under a lot of pressure. A change process is very frustrating for an uncertain person, and the whole situation generates anxiety. The person is physically trapped in this process and cannot affect nor escape from it, but rather adapt to it and develop new ways of handling it. The change might require modifications in daily routines in order to start adapting to the new situation, even though the person affected might not agree with it. Attitude and values about life are something people have developed personally for years, and therefore it is very valuable to them and painful to change or modify. There will always be passive, resistive and collaborative people in a change process and these can be identified in order to cluster and determine the level of support needed. (Schapira, 2013)

In order to overcome uncertainty information and guidance based on evidence, competence, and clarity, need to be delivered to the uncertain person at a convenient time. Also, regular two-way communication can help decreasing the sense of uncertainty since continuous work can have positive impact in terms of always giving regular feedback to the person in need. If important or emotional information is delivered in the wrong way to an uncertain person the uncertainty level will increase drastically. If the messenger or deliverer of the message is sad, stressed, irritated, or worried, it will directly affect the person who receives the information, and this can lead to devastating results. Every person is individual, and therefore the response to every individual person needs to be personalized. In order to customize the response the messenger needs to get to know the person better and understand her or his situation and worldview. There will be some people that want to know everything and all the details

available, while some people say the less the better. Regardless of what of information is requested, the messenger needs to be aware of that the information will have impact on the uncertain person somehow, whether it is in a good or a bad way. (Schapira, 2013)

People will react differently, and in pressured and uncertain situations the reactions tend to increase drastically. Depending on the person's past and new experiences, the new information can result in traumatic and stressed situations if the person finds the information to have a negative impact on the situation. Another uncertain person might instead find the information very useful or at least not too bad, and will not be affected by the information when it is delivered. (Tyrstrup, 2014) However, this can result in a situation where the person later on realizes that the information really hurt and starts to handle and process the new information first later on. Neither the messenger nor an uncertain person will know how the information will be received beforehand, which also makes the process very uncertain. The only way to handle this uncertainty in the process, and to decrease the uncertainty for the person, is to ask the person how she or he wants the information to be delivered, and then listen to that. The messenger needs to establish a relationship to the uncertain person built on trust, because in order to help the person to decrease the uncertainty they need to be able to find trust in something uncertain (Schapira, 2013)

When a messenger and a person have established this relationship built on trust, the person can start to let go of some uncertainty, and it is vital to let the person do so without interruption. Therefore it is important that this relationship can grow, and do so without having to change messenger. Having to change messenger can destroy the trust built up between the two parts and increase the uncertainty. The entire build up trust process needs to be built up once again, and the second time will most certainly require even more effort put in from the messenger in order for the person to let go of the uncertainty and start trusting the messenger. (Schapira, 2013) When a change is brought on and a person has to change and start over, the person can get lost in the process and be left out of the system, either on purpose by the person or accidentally by unwanted system gap not covering up good enough process wise. The gaps can be lack of information or knowledge, or miscommunication between different actors. (Tyrstrup, 2014)

2.2 A KNOWLEDGE SHARING SYSTEM

Knowledge by definition is “Facts, information, and skills acquired through experience or education; the theoretical or practical understanding of a subject” (Oxford university press, 2014). Knowledge is in other words processed information and data and could be viewed both as a thing and as a process where a person active acting and applying its expertise (Zack, 1999). There are two types of knowledge, explicit knowledge are knowledge that has been captured, codified, documented and could be shared and stored for a later reuse in a structural manner. Tacit knowledge is the knowledge that is hidden in the mind or in the muscle memory and may remain there if a person not is able to codify and document it or if it not is shared for example through experience or conversation. (Lynne, 2001)

Explicit knowledge is playing a large role in today’s organizations. Without structural manuals, checklists, guidelines and instructions, people would act in different ways according to each other and the ability to reuse knowledge already processed would be minimal. (Zack, 1999) The organizations processes would in that way not be standardized and effective as desirable. Some people argue that documented knowledge not is the key for success in organizations. Instead they lift the communication, good sharing processes and face-to-face

interaction as most important factor for knowledge reuse and development for organizations. (Lynne, 2001) To be able to stay competitive and effective, organizations need to see the knowledge as a valuable asset and handle it both as an object and as a process to be able to manage problems and explore opportunities. Even if organizations are aware of the importance of knowledge management many of them do not use the full potential of it and therefore never improve their performance. Many large organizations today are very complex with several parallel and cross-sectional processes. This makes it even more complicated to share, locate and get a solid base for knowledge reuse. (Zack, 1999)

Knowledge can also be divided into general and specific knowledge. General knowledge is broad and can be understood and shared by independent events and communities. Specific knowledge is context-specific. It could for example be knowledge that exists in a certain organization or in a specific field. Specific knowledge is harder to understand and need to be put in a context in order to contribute to an individual or a group. Furthermore, specific knowledge is perceived in different ways even within an organization. To define the most important key elements and business features for a customer could vary a lot depending on area of interest and position of the individual. (Zack, 1999)

2.2.1 COMMUNITIES OF PRACTICE

To be able to preserve and take care of the knowledge that is available within an organization it is important to develop tools to facilitate knowledge sharing and stimulate the continued creation of knowledge. Communities of practice are one way to stimulate knowledge sharing and collect explicit, tacit, general and specific knowledge optimally across natural borders. (Wenger, 2002) As of today organizations have internal boundaries between different work processes, geographical location, functions, and time. The organizations are specializing in these fields, but still need to share and communicate their in-house knowledge to everyone in the company. This is hard to succeed in if no communication system cross-boundaries exist. This is where a community of practice comes into play. A community of practice is a way of linking different parts of an organization cross-boundary, where a group of people is responsible of finding and sharing best practices, new knowledge findings, and encouraging people within the organizations to work together in order to improving their work more efficiently. (Hasanali et.al., 2002) The method is based on the creation of an open arena and a meeting place, where opinions, thoughts and experiences by different individuals regarding specific topics can be gathered. These individuals may have different backgrounds, experiences, and intentions with the participation in the forum. The purpose is not to create a new structure, but rather to open up the dialogue in order for an organization or a community to develop in new directions. By inviting and encourage different people to participate in the interaction it will be possible to obtain a comprehensive cross-border experience. (Wenger, 2002)

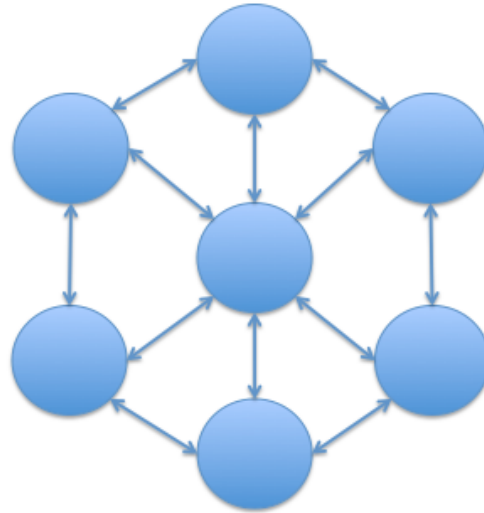


Figure 2.4 illustrates the interaction between different individuals in a community of practice.

In a community of practice, there will be different levels of participation. Furthest in is a small committed group of people who actively participates in activities and pushes the discussion to new levels. Outside this group additional individuals are more or less involved in the elaboration, although not as committed. Ultimately, there are peripheral activities and an audience with an interest in the situation but a silent participation. The audience and those who frequently participate in distance and silent forms are key players in the community. Many of these are insiders with deep understanding of a subject or a problem. They have competence and knowledge that could be used if only they have the tools to communicate it. (Wenger, 2002) Organizations have a tendency to get stuck in their silo structure, where every department or division of the organization does what they know and stop there. However, they sometimes need to cooperate with each other shortly, but the cooperation stops right after. This short interaction of cooperation is an organic form of communities of practice, informal, where employees feel the need of cooperating and sharing the knowledge and information they have within the organization. This helps the employees perform better in their work and conduct it faster and cheaper, but since there is no system providing opportunities to easily shared with the entire organization. Organizations have realized the benefits and advantages with the shared knowledge strategy and are now working with strategically development of formal communities in order to support the sharing of knowledge to the entire organization. (Hasanali et.al., 2002)

Communities of practice need to be created so that the participants feel a as full members and a natural level of comfort. It is important that participants know that they would not be bind to action plans and that they can give advice and "their views" without feeling requirements for continued contributing. If the community or group see that collaboration and the discussions gives value to the organization in one way or another they will often continue to work. (Wenger, 2002) Developing a community of practice strategically will nurture a self-creating knowledge community that shares the knowledge within the organization in an efficient way. People involved will see it as a routine and embrace it, rather than seeing it as a burden. The organization will be able to benefit from its own knowledge sharing and decrease the boundaries set between different divisions within the organization. (Hasanali et.al., 2002)

The rhythm of the group interactions is also strongly influenced by the rhythm of the organization as a whole or by the rhythm of the community. Is the rhythm and pace of change

too fast, people will feel out of breath over to catch and will pass to participate. If the pace is too slow the whole process feels lag and cumbersome. What you ideally want achieve is a combination of small group gatherings and an entirety to the community. The optimal rhythm is difficult to find but vital to an organization or society to evolve in the right direction. (Wenger, 2002) There are said to be four different kinds of communities of practice with different intentional strategies: helping communities, best-practice communities, knowledge-stewarding communities, and innovation communities. (Hasanali et.al., 2002)

A helping community focuses on connecting people within organizations cross-boundaries, due to the trend towards team-based and specialized divisions within an organization. This system helps sharing knowledge among individual specialists since they become more and more isolated from one another. They can meet and informally discuss their own challenges and findings, and get help, expertise and understand different perspectives from other employees working within different departments. This saves lots of time in terms of development and prevents new solutions to be developed twice. While helping communities focus on connecting people and let them gain information individually, the best-practice communities focus on developing the best suitable, efficient and beneficial practice possibly. The members of these communities continuously work with developing the practices and implementing the best ones. Cost reductions and an increase in process quality will be the results of the standardization of practice. This will however decrease the individual helping relationships.

In order to help satisfying the individual need and the need for knowledge within certain fields of expertise, the knowledge-stewarding communities help. This is a group of engaging people working with structuring the knowledge and sharing it within the organization. They can host forums where they locate, structure and disseminate the knowledge employees within the organization use on daily basis. This community nurtures productivity and increases the overall knowledge levels in the organization. In order to create an even higher level of productivity and flexibility, and in order to increase the innovativeness of the organization, innovation communities are created. The main responsibility of this community is the creation of increased cooperation and communicating between employees from different divisions within the organization. Employees will be encouraged to share and get help with new ideas and practices, in order to foster an innovative and flexible environment and culture. Developers can get help from market analysts with forecasts and market demands and needs. (Hasanali et.al, 2002)

2.2.2 INFORMATION

People want to learn and gather lots of information before, during and after coming in contact with a diagnosis of any kind, as a patient or a relative. Years ago doctors and other actors involved in the treatment process provided the information, but nowadays people are not satisfied with one source of information. Internet has exploded with access to lots of different sources providing information about basic health knowledge, articles, conditions, therapies, and personal experiences. They are actively searching for information and options to fit to their individual needs, in order to restore or improve their situation. This behavior is increasing with more and more technology, and therefore it is important for the different organizations designing the information to get to know the needs of the information searchers. The search for information is very often triggered by a diagnosis, regardless of the relation to the diagnosis. The knowledge gap is then the driver of the searcher, where the gap is to be filled with the information they think is needed. The searcher is not satisfied with the current

knowledge situation and wants to increase the knowledge level and reach their personal goal level. Depending on the diagnosis, the searcher can be looking for information on daily basis or more seldom. (Jones, 2013)

2.2.3 INFORMATION SEARCHERS

When searching for information some concerns in the daily life of the searcher will focus the search in different directions. Back-pain, sleeplessness or a chronic condition will affect the searching. The mood of the searcher will also be affected, and at some point in time the searcher might experience a change in identity: to become a patient. Therefore it is important to consider the entire process of care when providing information, from the healthy stage to the end of the treatment, and even further. The entire process perspective does not only include the patient, but family, relatives and friends. A serious illness affects people in the surrounding of a patient, the information searcher. If the result of the process is positive, all people involved will be survivors and winners. The emphasis of the process has shifted from one single person, to a team of fighters. This put larger emphasis on need for information, provided for both the patient and relatives at different stages in the process. The information providers need to know what the customers need in order to reach their individual goals. (Jones, 2013)

Jones says in his book that Taylor described four types of needs when having unanswered questions: visceral, conscious, formalized, and compromised need. The visceral need is about the need of information a person needs but does not know it, while the conscious need is the need the patient knows is needed. The formalized need is the actual question about a need, and the compromised need is the when asking about information to satisfy the need. These needs are the needs of an information searching patient or relative. The public sector organizations have started to care for the information searching process and the people searching, in order to see what information is requested. As of right now the most important information needed is to understand what is wrong, get an idea about the prognosis, and how to assist in self-care. The information is used in order to make critical decisions in the process of treatments, and therefore it is important that the information does not mislead or misguide the information searcher. The information will guide the searcher into certain direction and if the information is biased or wrong, there will be consequences to the individual person. It is also important to understand that the information searcher is very emotionally oriented and information regarding the subject will affect more than scientific information. (Jones, 2013)

2.3 CHANGING AN ORGANIZATION

When an organization is about to change there are many perspectives and possible problem areas to consider and to investigate, before starting the implementation of a change. The following section will further develop an understanding about the general perspective of an organizational change, and the change of the public sector organizations.

2.3.1 GENERAL PERSPECTIVE OF CHANGE MANAGEMENT

In their article, Nadler and Tushman (1997) claim that changing an organization is to go from one, current, state to another, future state. The aim is for the future state to be successfully implemented with the new change. During this process it is key to have a clear vision and picture of the future state, because the organization will gradually face new problems, which have to be handled efficiently. Three specific problem areas are addressed: power, organizational control, and anxiety. The problem of power means that there will be confusion

and frustration among the employees when changing the structure of the current state into the new state. This will modify and intrude on the balance among the employees and question the importance of their work, which can lead to confusion and a rebellious mood and environment. The power can therefore be questioned and decreased due to the lack of trust and motivation among the employees towards managers. (Nadler and Tushman, 1997)

Regarding organizational control old control systems or unwritten control activities could be ruined when transforming the organization into the future state. These ways of controlling might have been important for the structure and for management, in order to establish a safe work environment. An organizational change could ruin these systems and therefore affect the structure and the trustworthiness among the employees. This in turn could have a negative impact on the organizational control. (Nadler and Tushman, 1997)

Anxiety arises among employees when an organization is about to change. A change greatly affects the employees in their work environment and in their way of thinking, and by nature this creates an uncertainty and an anxiety. There will be many questions from the employees regarding whether or not they will be needed in the organization in the future state. If they do not receive any answers this can easily generate stress and resistance to the change, which in turn can affect the work ability and the overall performance. (Nadler and Tushman, 1997)

3.1.2 CHANGE WITHIN PUBLIC SECTOR ORGANIZATIONS

There are large differences between public sector organizations and private sector organizations in terms of how to bring about a change, and if the change can or should be implemented. The purpose, the culture, and the environment public sector organizations operate in are less flexible due to governmental rules, regulations, and many different interests. There are stakeholders pointing in certain directions for the public sector organization to go, rather than managers planning a future state for the organization to reach within a few years. Public sector organizations are not to maximize profit in order to increase stakeholder wealth, but rather deliver public sector, and deliver it in an efficient way. However, the understanding of how to do this in the most efficient way changes when political targets and priorities change. (Ostroff, 2006)

As of today, development of improvement processes and actual implementation of change projects are going very slow in public sector organizations, even though many large improvement areas were discovered years ago, and are well documented. Acceleration in the development of these processes would require a major change in the entire organization system, where the culture and attitude of the public sector stakeholders and employees would have to change first. (Berwick, 2003) Improvements need to be involved in the everyday work in order to provide the very best help and care. All improvement work means change, but it is not always the other way around, because there have to be accurate measuring systems in order to map the improvement work and see if the results point in the right direction. (Batalden and Davidoff, 2007)

Also, different kinds of knowledge systems are essential in order to gain knowledge about how to learn, and an organization needs to know how to learn, in order to learn more efficiently. One of these systems is about gaining knowledge about how to develop measurement systems and techniques with respect to the time aspect. This means considering the fact that improvement projects involve change processes over time, where the aim of the projects may have to be flexible in order to cohere with reality. It is also of importance to

recognize and reward the employees working within change projects, and to decide how they will be held accountable for the results of the projects. In public sector organizations it is not only to deploy these knowledge-seeking activities and leave it to the employees, but rather trying to involve the entire organization to participate and do so every day. In order to involve everyone and establish a work culture with daily change or improvement work, employees have to be aware of their situation and have the knowledge and leadership needed in order to bring on change. (Batalden and Davidoff, 2007) As of today, accordingly to Berwick, there are many old theories and models in favor of standardized working procedures where all employees do what they are told. (2003)

More modern and more efficient would be to engage the employees in the improvement activities, in order to jointly decide valuable aims, measure results, and come up with new and more efficient ways of working. This does however require an effort from the employees in terms of knowledge gaining and understanding of the work results. It will make the healthcare employees aware of that they firstly have to do their everyday work tasks, and then improve them. (Batalden and Davidoff, 2007) The involvement of employees in improvement work does also require a very high degree of trust and structure, where the employees need to be open minded about team based work environment, take responsibility for their own actions, and deal with upcoming problems instead of blaming it on external factors. This can be seen as standardized work, in order to create the structure and habits needed in order to get it into everyday work. Changes will require some after work in order to make the organization stay with the new structure and standards, which can call for some structure standardizations. (Berwick, 2003)

3. METHOD

In this chapter the methods used in this study are described. The research design, literature study, data collection, and data analysis chosen in order to fulfill the purpose of the study will be explained and motivated. Ethical aspects and a source evaluation will be discussed in the end of the chapter.

3.1 RESEARCH STRATEGY AND PROCESS

Since the purpose of the study is to understand the perspective of participants, rather than analyzing quantitative data, a qualitative research approach is preferred. A qualitative research is robust, and it is helpful when not too much information is available about a certain subject. It is also preferred when the collected data needs to be analyzed, in order to give a comprehensive and people-centered view of the research. The qualitative research approach aims towards understanding how people as individuals or in groups perceive and interpret different phenomena. (Malagon-Maldonado, 2014) An inductive and interpretive orientation has been applied to this qualitative research approach. Inductive reasoning is basically a bottom up approach where the research starts by observing specific settings and phenomenon, and then moves towards a broader perspective with theories and generalizations. (Bryman and Bell, 2011)

The inductive orientation is argued by Bryman and Bell (2011) to be very useful when no clear hypothesis has been defined before the start of the research. Also, it is said to provide great insight in research topics when complexity is to be studied. The interpretive orientation is about understanding social phenomenon and social settings, and the interpretations of participants, instead of using scientific theories and models before studying the social world. (Bryman and Bell, 2011) The chosen study design has enabled the researchers to be open-

mindful and eager to look for data not only collected from the regular sources, but instead also look for unwritten and unexpected data valuable for the result of this study. In the theoretical framework there are no predetermined rules to follow, but instead the literature is to be determined by the qualitative data. This qualitative study design enables the research to focus on human experience and how organizations perform, which makes it suitable for research in healthcare where the participants involved can show their reality including both patients and organization. (Malagon-Maldonado, 2014)

The selected research process is based on the model introduced by Bryman and Bell (2003), and is illustrated in the Figure 3.1. Through this model the process is visualized and the guidelines are clearly presented and simplified. (Bryman and Bell, 2003) The process is iterative and the loop on the right, with the extended data collection step, was therefore repeated until enough valuable data was collected. (Cammack et.al, 2008)

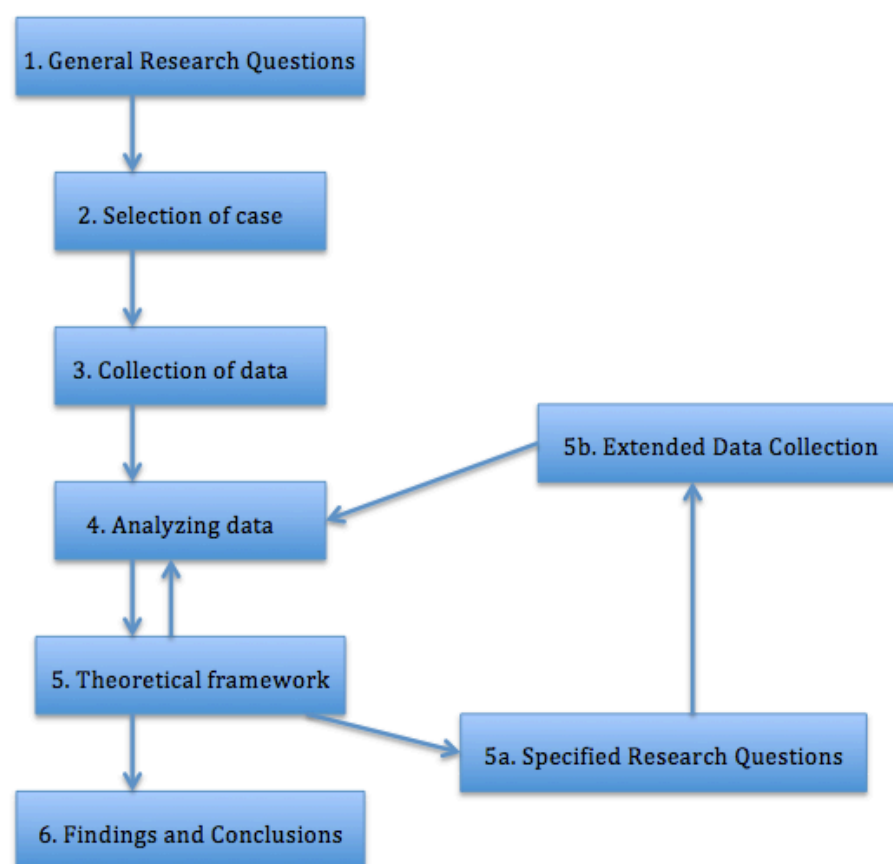


Figure 3.1. The qualitative research process (Bryman and Bell, 2003)

3.2 RESEARCH DESIGN

The research design is the framework and guidelines used for collecting and analyzing data. Criteria and priorities in the research will help forming the design, in order to assess the quality of the study. (Bryman and Bell, 2003) In this specific study the qualitative study was applied as the research design. Several people were interviewed and analyzed simultaneously during a short period of time, in order to understand and provide valuable data regarding behaviors and experiences. The data was further analyzed in order to understand the findings

in a broader perspective. A qualitative study takes the complexity and the nature of the problem into account, which in this study is of specific interest. (Bryman and Bell, 2003) The strength of a qualitative study is the flexibility and the adaptively to changes in order to collect the most valuable data. An additional advantage of a qualitative study is the use of multiple sources of evidence. (Bryman and Bell, 2003) The chosen research design has therefore helped structuring the choices of data collection methods.

3.3 DATA COLLECTION

The data collection will be based on information from many different sources, and be gathered through different methods in order to consider triangulation; to look at the problem from different perspective (Bryman and Bell, 2011). Qualitative research methods have been used in this study in order to collect data from both primary and secondary sources. Semi-structured interviews have been the most commonly used method for collecting data from primary sources, but conferences, meetings, and workshops with different authorities and occupational categories have also been used in order to further collect valuable data. To support the primary data secondary data such as documents and statistics have been collected. All of the qualitative research methods will be further elaborated in the sections below.

Since the study focuses on the relation patient - healthcare - the Försäkringskassan, the interviewees have been primarily chosen from these areas of knowledge. In addition, some experts in the field of study have been interviewed in order to further analyze the collected data, and to get opinions and views from people engaged from the outside of the involved actors. In the situation of interviewing patients there is a strong relation to ethics, and therefore the researchers only interviewed patients declared healthy, and who were involved in a patient council group working with cancer process improvements. The patients could therefore volunteer to be interviewed. The healthcare employees interviewed were people involved in improvement projects related to RCC and the Försäkringskassan, and therefore had valuable information and knowledge about the project. The employees at Försäkringskassan were chosen based on their location of office. The Skövde office where they work is on of the offices in top of improvement projects when it comes to cooperation with the healthcare organization. They have started some projects and therefore the researchers chose to interview them. The experts in the field were chosen due to their richness of ideas and opinions, and the long experience of communication and integration projects in healthcare.

Databases, websites and books will contribute to the theoretical framework and provide information and knowledge about the field, and what gaps in research the results of this study can fill in (The University of Queensland). This will generate information about how to prepare an organization for a change, and the current problems, where methods and processes are described and discussed, but also with future state methods discussions where other possibilities are being described.

3.3.1 INTERVIEWS

In qualitative research interviewing is the most commonly used method, due to the flexibility it contributes to. To interview and transcribe is very time-consuming, but the richness of the data and the flexible processes convince the researchers of the positive aspects of the method. (Bryman and Bell, 2003) The interview methods used in this research, also referred to as qualitative interviews by Bryman and Bell (2003), are unstructured and semi-structured

interviews, which contribute to flexible interview process. A list with the interview names and organizations is to be found in Appendix I.

In the beginning of the research unstructured interviews were conducted with previously diagnosed cancer patients in order to gain deeper knowledge and an overall understanding of the problems of the study. With unstructured interviews the interviewees can elaborate and explain their answers, as they prefer, while the interviewers can gain lots of valuable unexpected data and perspectives. This method is preferred when little knowledge exists about the problem within the research team before the research takes place. (Bryman and Bell, 2011) The unstructured interviews are time-consuming in terms of conducting, transcribing, and comparing the answers, but in this research it was not considered a problem since it was only used in the beginning of the data collection.

The interviews provided qualitative data regarding the current state of the problem. The researchers then planned semi-structured interviews, both face-to-face and telephone interviews, in order to get a good flow with pre-planned questions, and follow-up questions. This enabled the interviewees to answer as thoroughly as possible, but with some guidelines in order to decrease the time needed to compare and to analyze the answers. The guidelines were questions in an interview guide created by the researchers, where the questions were sorted based on topics, which led to answer within the areas of interest. (Bryman and Bell, 2011) The questions in the interview guide changed due to different interviewee expertise, and the purpose of the interview. Also, the knowledge level within the research team increased and therefore some questions could be deleted while new questions arose. These semi-structured interviews were the main method used for data collection. The different interview templates can be found in Appendix II. The interviewees were patients, employees at RCC, employees at the Försäkringskassan, patient relatives, doctors, nurses, healthcare coordinators, and healthcare counselors. The broad range of interviewees was intentional in order to get all possible perspectives of the process, in order to consider triangulation. (Bryman and Bell, 2011)

The majority of the interviews with patients were performed via telephone and lasted for 40 to 90 minutes. All data gathered from doctors, nurses, and healthcare coordinators were conducted in person both through interviews, but also at cross-functional meetings, and were between 30 to 120 minutes in length. Some employees from the Försäkringskassan also attended the cross-functional meetings. The rest of the interviews with employees from the Försäkringskassan were performed via telephone and lasted for about 60 minutes. Interviews with experts in the field were conducted via telephone and lasted for 60 minutes, with some email correspondence afterwards in order to get additional input. In total 20 interviews were conducted during the study.

3.4 DATA ANALYSIS

In qualitative research the data collected from unstructured and semi-structured interviews tend to be of large amount and without any specific structure. This complicates the analysis of the material and makes it rather time-consuming to handle. The qualitative data is rich and attractive and therefore guidelines and well structured methods of analyzing the material is needed. In this study the grounded theory introduced by Bryman and Bell was used in order to guide the analysis of the collected data (2003). The grounded theory is said to be iterative, where the data collection and the data analysis are repeated several times referring back to each other since the analysis brings new knowledge to the researchers. When the new

knowledge is gathered additional data collections steps in new directions can be conducted, and the new data needs to be analyzed. The most valuable tool or process in grounded theory is coding, where the collected data is broken down into categories and given labels. The analysis was conducted right after the data was collected, and then once more after the entire data collection was complete. (Bryman and Bell, 2003)

After the interviews were conducted the data was divided and grouped into a few large groups based on the type of the data. It could be a common theme, words, or opinions that connected the data. These findings raised arguments and reflections on the subject. The groups were then further divided into smaller groups, where more arguments were discovered. Many questions also arose around how to make a standardized process more individual, and therefore a theoretical framework was conducted simultaneously with the data analysis in order to explain the answer the findings from the analyzed data. The findings from the data determined what areas of investigation were needed in the theoretical framework, and after the framework was set further data collection from secondary sources was conducted and analyzed with help from the theoretical framework.

A very important part of the data analysis was to determine the real problem in this specific study, and how to solve it with help from the theoretical framework. To help clear this out the tool effective scoping was used and carefully analyzed. Effective scoping is a tool commonly used in improvement projects, and it is very efficient and helpful when determining a problem in a specific situation. It is a map guiding the researchers through the work of specifying the problem with help from pre-determined questions to answer in a specific order. All data collected in the study was considered and taken into account, where the most prevalent and valuable information was written down as answers to the questions on the effective scoping map. During the study more and more data was collected and added to the map and analyzed in order to follow the grounded theory. This helped developing the map and increase the quality of the analysis of the data. Considerations regarding the input, the output, how to measure these, and what to expect in the future were all documented. The full picture of the effective scoping is to be found in Appendix III. Since the focus of the study was to see the process from a patient's point of view, the results of the effective scoping have the same focus.

3.5 RESEARCH ETHICS

Ethical issues are of highest concern in when studying processes involving people, and information confidentiality. The researchers cannot ignore these ethical issues, and it relates to the integrity of the research, and the disciplines involved. It is a matter of treating the involved people in the right and most suitable way, and closely determines what actions and activities to involve in the study. It is important to be aware of differences in personal values and beliefs. Any ethical guidelines in the field of study should be followed, in order to protect both the research participants, and the researchers. (Bryman and Bell, 2003) The areas of issues that are to be protected by ethical guidelines are accordingly to Bryman and Bell (2003): harm to the involved people, lack of assent, violation of the individual privacy, and whether fraud is involved.

Harm can occur if the participants get stressed, or if the information is leaked. The researcher carefully needs to respect the confidentiality. The lack of assent can occur if the participants are not informed about the research objectives, or if the participants have not agreed or fully understood their role in the research. Violation of privacy is about the researchers not having

the right to invade in a participant's personal and private life or values, without permission. This is very closely linked to the lack of assent, because there needs to be an agreement before involving a person. Fraud occurs if the researchers decide to present the research as something other than it is. This leads the participants into something they might not want to participate in, which can result in harm to them. (Bryman and Bell, 2003)

In this study the researchers have considered the research ethics very carefully. The results are presented in a fictional story about a woman named Emilia. The researchers gathered data, clustered it, and concluded it in this life event of Emilia. Therefore, no personal information or names are presented in such a way that it could link back and identify the interviewees who do not want to be identified. The story about Emilia is a result of all the information, knowledge, and data gathered in the data collection, which illustrates what a life situation of a cancer patient could be like. All of the written material has been handed out to the interviewees who requested to read it before publishing, in order for them to confirm the trustworthiness of the text.

3.6 SOURCE EVALUATION

Reliability determines to what extent the data or the measurement is consistent, which means how well the data collected from different sources match. Validity is about if the findings are generalizable to the population, if the instruments used in the study measure the correct measures, and if the findings are interpreted correctly by the researchers. However, researchers with qualitative approach argue that validity and reliability are designed for quantitative research, and that these two concepts are difficult or not worth using in qualitative research. (Hernon and Schwartz, 2009) Instead, Hernon and Schwartz (2009) propose qualitative researchers to use the concepts of credibility, transferability, dependability, and conformability.

To establish credible findings the research needs to be carried out in good practice, and the findings need to be shared and confirmed by the social world to be correctly understood by the researchers. The credibility criteria are in line with the internal validity criteria for quantitative research. (Bryman and Bell, 2003) In this study multiple interviews with different people from within the same area of knowledge have been performed, in order to ensure that the data collected correlate with the actual reality. Also, interviews with experts in the field were conducted in order to confirm the accuracy of the collected empirical data. If the study is transferrable it means that the findings of the study are generalizable to other situations where social settings occur, or to a similar situation as the one studied but at another point in time. (Bryman and Bell, 2003) The main source of data collection in this study is interviews with people involved in the process, and therefore the findings are specific for this type of constellation. The findings might be questioned in terms of the transferability to other contexts of social settings, but can most definitely be transferred to other similar constellations.

Dependability is whether the study can be replicated and still result in the same findings. (Hernon and Schwartz, 2009) The public sector organizations, as written in the study, moves rather slow in the improvement of the processes, but improvement projects are continuously adapting the systems to more efficient solutions. Therefore, if the study would be replicated rather soon the results will most likely end up in the same findings, but if it is replicated in a few years, the study will result in other findings due to continuous improvement work. Regarding the conformability, it refers to the objectivity of the researchers in the conclusions

of the study. (Hernon and Schwartz, 2009) The researchers in this study tried to increase the objectivity as much as possible through presence of both researchers at all interviews and activities where data was collected. Complete objectivity is impossible, but the presence most likely increased it.

3.7 REFLECTION

All decisions made throughout the study affected or influenced the final results and outcome of the thesis, where especially the choice of research questions and the overall research strategy greatly affected. The qualitative research approach has flexible advantages, but it can at the same time deliver lots of data, which makes it hard to manage the analysis of the findings. The time was limited and therefore the data was collected mainly from the key persons in the studied process, and the aim was to deliver results connected to the patients' point of view. Due to this, the data collected and the findings are biased. To increase the degree of validity a quantitative research could have been applied instead. However, the flexibility and the values from the qualitative research approach would then have been lost, and so would the valuable findings collected from the interviews have been.

The focus of this thesis was the patient's perspective of the process, and therefore the data collection and the analysis had this focus. If the focus would have been the organization's point of view, the outcome and the results of the thesis might have looked completely different, and the conclusions and recommendations could have differed. The healthcare organization and the Försäkringskassan have been involved in order to get their point of view as well, but the findings and the final conclusions had the focus of the patient's point of view.

4. EMPIRICAL FINDINGS

This chapter will present the results from the collected data in this study. The results from the interviewed patients will be illustrated as a fictional story about a woman called Emilia. Her story will be told after a shorter introduction of how the life of a cancer patient can differ from others.

4.1 VARIATION OF INPUT

Within the life event of getting cancer in the midlife there is currently a wide variation of parameters that the person will get in touch with. An instant picture the 4th of march 2013 report 1145 persons between the age of 30-60 years registered on sickness allowance as a result of a tumor diagnosis in Västra Götaland and Halland region. (Försäkringskassan, 2014) When a patient receives a cancer diagnosis, there are many surrounding factors which affect the individual's life situation and that must be taken into consideration for further evaluation and correct treatment.

The variation of the patients that are in midlife consists of differences in age, gender diagnosis and treatment modalities. The variation also consists of different family configurations where children and relatives may look differently for each person. There are also large work-related variation, which can be manifested in different forms of employment, work-tasks, employers' attitudes to cancer disease and the ability to return to work. Depending on the time of treatment, there is also a large variation around the conditions and possibility that a person

may be able to return to the same work as before or be forced to find another more suitable environment.

The variation for patient also involve physical conditions, the impact of the treatment and the physical shape patient had as a basis. The mental part is also of great spread when everyone handles a life situation differently and in her or his own way. Some patients want to be involved in their own treatment and assessment while some are increasingly devolving responsibility to specific operations, healthcare and agencies. Although the economic environment is also something that today is considerable variation between patients. The factors and the variation found on a patient's situation could be considered as infinite. Each individual has a unique situation and are in need of custom solutions.

4.2 CASE STORY

The case story is based on qualitative data gathering through interviews with patients. Patient sources can by confidentiality reasons not be published. The case story is extreme of its kind and point to events that may occur during the life event of getting cancer in midlife. The story aims to demonstrate the challenges that patients and the public sector encounter during the journey of fighting against cancer. Emilia are only one person, which reflects her life event. It is important to understand that as many people there are living with cancer diagnoses, as many different life events exist.

4.2.1 EMILIA'S STORY

In the year of 2011, 8427 women got a diagnosis of breast cancer. This story is about Emilia who is one of those women. She is a fictive person that combines experiences and thoughts from all patients who participated in the study.

Detection of something

Emilia turned off the treadmill, wiped the sweat off her forehead, and walked with tired steps into the bathroom. Friday night. She looked in the mirror and turned the shower on. It felt like she needed this, to start exercising more and simply prioritize to take care of herself. She went into the shower and reached for the soap. The bottle cap was broken, and apparently the children had tried to fix it with a piece of sticky tape. She laughed a little to herself as she lathered up. Suddenly she felt something odd. A tiny little hard lump located on the side of the right breast. She tried to feel what it was, changed the position of the arm, and felt once more. She turned the water off and took a step out of the shower. She looked in the mirror and felt the lump again. The panic came immediately.

She was not the one who ran to the emergency room just because a child had a little fever or a scratch, and likewise she reasoned about her own health. Now however, she was concerned. A lump in the breast could just mean one thing, right? She walked through the quiet house, and the three kids were asleep. The only creature awake was the cat. Wearing a towel, she sat down at the computer and googled "lump in breast" and yes, there were the descriptions of many cases resulting in cancer. She knew googling health concerns is not the most appropriate way of getting information, but somehow it was satisfying to research. The panic increased when she read medical description, and then personal descriptions about living with cancer. Even though it was late, she had no peace to go to bed. She walked around, felt the breast over and over again. In desperation she picked up the phone, and called the Swedish medical support line.

A calm female voice answered. Emilia tried to keep it together, and she swallowed her tears when she told the woman about her lump. The woman said that it could be something serious, but also be something totally harmless. She suggested Emilia to go and check it out on Monday. On Monday?! The panic was back. It was Friday night and of course nothing was open until Monday.

The weekend was just a big blur. She called her friend Nathalie and asked her what she thought it could be. Nathalie did not know, and she tried to support Emilia and said that it might just be some harmless gland. Emilia was not satisfied, and nothing could cheer her up. When Monday finally came Emilia called Sahlgrenska and got an appointment three days later. The waiting time felt like a year. Over and over again she felt the lump, and unfortunately it did not decrease. She met the doctor and got a referral to mammography a week and a half later, and the waiting was on again. She slept bad and felt alone, with nobody to share her thoughts. She reasoned that there might just not be such a good idea to call Nathalie in the middle of the night again. Instead Internet was her best friend, but also her worst enemy.

Emilia had divorced six months ago. She both loved and hated the solitude and she had managed to all by herself keeping the house, so the children could stay where they used to. The hardest part with living alone was to manage everyday activities, and the economical situation. Her youngest child was only 4 years old, and the other two, 7 and 10. It was tough to live on only one person's salary, and the two oldest children wanted to participate in several activities outside school, which of course cost a lot. Emilia liked her work as a teacher in one of the elementary schools close to her home. She liked to see the children learn new things and laughed with them every day. This week it was different. She could not concentrate and neither focus on the children's questions.

The mammography was painful and hurt, but at the same time it felt so good to be in hands of the doctors that actually took care of her. Now she really needed an answer. The ultrasound, and later on a cell sample went quite smooth, and once again the waiting time was the hardest part. When she after another week drove the car at the highway towards the clinic the positive thoughts was mixed in a large cord tangled with the most horrible ones. What if it was what she feared the most?

The diagnosis of breast cancer

The wind grabbed her hair when she got out of the car. Spring was late and she could still see some piles of dirty snow in the corners of the parking place. She entered the building and looked at herself in the mirror of the elevator. She looked tired with dark marks under her eyes; the sleep had been minimal for the last weeks. The waiting area was empty, and she sat down. She was worried about what to expect and the thoughts were spinning around. In a few minutes everything could be just fine, or the totally opposite. The doctor finally came, took her hand, asked how she had been for the last days and showed the way through the corridor to a room.

Emilia will always remember this meeting, the blue and green painting on the wall with a cat that looked at her, the clock that was ticking muffled and the feeling of the typical visitor chair with dots. The doctor said that the samplings of the tumor had been sent to the lab the last week and that the result now was back. It showed that this is a malignant tumor Emilia and that means that we have to start a treatment. Emilia felt it like the world just turned upside

down, she couldn't feel the floor and it got black in front of her. The following information was like a blur to her. She remembered herself asking questions but she could not in the afterwards remember the answers. This was March 28th 2011; Emilia was 41 years old and had got a message that no one ever wants. She got diagnosed with breast cancer.

Everyday life changes

Life suddenly turned upside down. The everyday challenges with food, bags for the kids, and work were exchanged with hospital visits, counselor calls, and many concerns about the future. The waiting time was almost the hardest part. Waiting time between samples, medical calls, and the uncertainty. Would the doctors be able to treat the cancer?

Emilia sometimes felt like her mind was not in the right place. She had a hard time processing information, and remembering what the doctors told her. She could possibly not interpret the meaning of the diagnosis, and the treatments and the possibilities of being medically cured were hard for her to picture. Very often she processed and went through the dialogues with the doctors over and over again. It resulted in confusion and she was not sure what was the truth, and what was her own imagination. Her brother came with her to most of the appointments, and it was good to have someone that could tell her what information was given, and how he had interpreted the situation. Emilia got a primary contact nurse to call if she had any questions or experienced problems. The nurse was connected and familiar with Emilia's personal journey through the life event of cancer, with treatments and personal challenges. Emilia felt secure and satisfied to have someone to call when she had concerns, or when she had mixed up the information from the meetings with the doctors.

Her brother was a great support, and he assisted her with everything she needed. The only thing he could not help her with were the children. They had their dad to stay with, but Emilia still wanted to spend time with them so badly when she was not tied to the hospital. Sometimes she got so worried when she watched her children play. How would life work out for them without their mother? Who knew their tears and laughter, as she did? Would Selma, her four-year-old daughter even remember her mother if the worst happened? Emilia knew she wanted to think positively, because the odds of becoming healthy and totally cured were still very high, but sometimes she just could not manage it.

The workplace

When Emilia called her work to talk to them she felt sad. She loved her job, and many of her colleagues were also her closest friends. At the same time, it was a relief to talk about the cancer and the life situation she was in. Her manager, a man in the early 50's was understanding and listened carefully when Emilia told him about the cancer diagnosis. He told her to take care of herself and get in touch if there was something he could do for her. After the phone call Emilia did not hear anything from him for a long while. Cancer was a topic that was sensitive and Emilia's manager did not know how he would react to the situation.

The first interaction with the Försäkringskassan

Emilia was concerned about approaching Försäkringskassan. Despite the fact that she only had good experiences with them, she felt unsure of how she would be treated. She had read a lot of negative press and media debates and releases recently, and that made her think that it probably would be difficult to deal with them. When she received the first letter it only took four days before the contacted her via telephone. She listened to the officer, who gave her advice and information regarding what opportunities she had. The officer suggested a personal meeting in order to get to know each other, and talk about the situation. It felt quite

good and the officer gave a good first impression, but she was still uncertain about how this could possibly benefit her.

After the personal meeting Emilia felt better. Försäkringskassan was not nearly as difficult to work with as she had imagined. Her personal officer also seemed to understand and engage in her individual situation. She received a direct number to call if she had any concerns or questions. Otherwise, they were supposed to have contact once in a while, depending on Emilia's situation. Emilia knew it would be harder to live with only 80 percent of her salary, but she could cut back on some expenses. The doctor had missed to fill in some kind of document completely so it would take another few days before she was able to get a total judgment of her work ability. That would also delay the final decision for her sick leave. Emilia had saved some money in the last few years, which she was very happy about right now. She could use that money while waiting for payment from the Försäkringskassan. Emilia felt frustrated when the money was late and acted out on the Försäkringskassan officer. He said he would like to do more, but that he had to follow the rules and the administration process. She got a guilty conscience afterwards but it felt good to release her anger and frustration. Could it really be impossible to obtain an exemption or other temporary economic aid in a situation like this?

Overall, she and the officer had a great contact. Emilia trusted his judgment, and he really cared for her and wanted to do the best for her situation. He was a support for her, and it was good that he had the courage to ask those hard questions, and talk about subject that no one else ever approached.

The treatment and time at the hospital

Emilia's cancer had started to spread to the lymph system, but it was still in the early phases. She started the treatment by getting chemotherapy, in order to slow down the growth of the tumor and the spread, before she could go through an operation and remove parts of, or the whole breast. Sometimes Emilia it felt secure to be in the hospital. At the hospital good things happened, and each new chemotherapy phase brought her one step further. She came closer to a healthy and "normal" life. At the hospital, she could let go of the control, and let the doctors be the experts. She could somewhat relax, and live more in the present. When in the hospital, she did not have to wait, and she was able to ask questions whenever she wanted.

The first treatment was tough. She feared in secret for the day when her hair was to fall off. She said to herself that it was silly, but she felt like the hair was a part of her feminine identity. The first sign she saw was the brush that was more full than before. She could not resist taking it away and trying to brush the hair again. It was full again after some swipes. After that she waited longer than normal to take a shower and clean her hair. She wanted to keep the blond curls as long as possible. When she finally did, there were big empty spots at the head. That day she started to look for a wig. When she woke up one morning the most of the remaining hair was in a pile on the pillow. Emilia gathered it and put it in a little box. She could not just throw it away. After one and a half months all of her hair was gone.

Every fourth week Emilia drove to the hospital. The week after chemotherapy she was not strong enough to take care of the children by herself, and her brother and his wife tried to sleep at her place as much as possible so that the children could be with her anyway. It was not only the physical effects of the treatments that were tough. Emilia had a growing inner anxiety about death, and what would happen if the treatment did not work. She cursed herself

over what she could have done better, in order not to end up with a cancer diagnosis, over and over again.

Children and relatives

Emilia wanted everything to be as normal as possible for the children. She wanted them secure, but still knowing the truth. How honest can you possibly be with children? Both the pre-school teachers and the school counselors were good support, but sometimes she wished there was something outside the school: someone who was professional dealing with children's issues having a parent living with cancer.

One question that arose when she was home between treatments was “How many hours was her youngest allowed to be at the pre-school?” She had not got any information about changes but a friend of her told her that it might be a good idea to look up further. She felt worried and was tired. She knew that Selma would have it a lot more fun at pre-school where the teachers could give her attention and where she could play with the other children. When she realized that the municipality allowed regular schedules she finally could breath out again.

Emilia talked very often with her assigned counselor; somehow it felt liberating to get out all thoughts and concerns. Very often she thought her brother would need more support as well, or at least someone to talk to. Someone in the same situation would have been good for him to talk to, in order to let go of the anxiety and feelings he dealt with. Sometimes she tried to talk to him about the situation, but some days the anger and disappointment just got too overwhelming and the situation ended in endless tears or an occasional fight. Her brother had a hard time handling his emotions, when at the same time trying to be the best support possible when Emilia went through her toughest periods. He very often felt guilty for focusing on himself and his feelings when it was Emilia that suffered the most.

Lack of information

Emilia sometimes felt like she was the one that had to figure out how to do everything, what papers that she should send at what time and how to fill them in. Often she had to call her officer and ask how to do with certain parts of administrative things. She got information when she asked for it, but there is no proper place when things were collected, and where she could read a bit ahead about what to expect next.

Often she goes out on the Internet on the late evenings and nights reading threads and blogs of other people. She knows that she sometimes get scared of things she recently read and have to call her contact nurse to ask if the information is correct. Sometimes she have read blogs which gave her hope and a willingness to continue fight against the cancer. The Internet is both a friend and an enemy but she could not help that she wanted to know everything that was even possible to happen to her.

Continued treatment and operation

One of Emilia's biggest concerns was whether or not there was going to be an operation or not. She thought is was no clear information about it whatsoever. The doctors said they probably would go through with an operation, but they had to wait to see if the tumor could decrease first. She also lacked clear information about what to do if they could not operate? Would they not do anything at all then? The doctors promised that they would do everything they could in order to keep her informed and updated, but the worry was still there and her questions got no answers. After a couple of months there was time for operation, and Emilia

both feared and longed for it. She had been thinking a lot about how she would feel without one of her breasts. However, she also somewhere got strengthen when she thought it was worth it. If that was the price to pay for her to see her children grow up, and be there for them in the future, she would definitely go through with it.

The operations went well, and Emilia felt great support and professionalism from the team doing the surgery. When she woke up the only thing that she could think about was that the tumor was out of her body. It had been removed, and the cancer could hopefully no longer do her any harm.

Continued interaction with Försäkringskassan

After some time Emilia got a new officer at the Försäkringskassan. Emilia felt not the same connection to her as she did to the first one. She had not the same understanding of Emilia's situation with stress, anxiety and physical fatigue. With the new officer she tried to find other ways to get more financial help, but the law was unswerving. Emilia knew she was the one supposed to send in her documents from the healthcare to the Försäkringskassan, and that it was her responsibility that they were correct and handed in on time. Sometimes she thought the Försäkringskassan officer mistrusted her ability and understanding of the task, especially when she accidentally sent in the wrong documents. It caused a lot of negative feelings for Emilia.

The economic situation

The financial stress affected her greatly. Her brother helped her with some money and the practical parts around bills when she was at the hospital. Emilia sometimes thought that she should be thankful that she was living in Sweden where the private medical expenses were minimal compared to other nations when you got sick but it was still a battle to manage to cover bills and everyday expenses.

She was happy that she had saved money during the years and that she had not bought that new car that she was looking at some weeks before she got her diagnosis. Instead she now could use that money as a backup, which she also was forced to do every month. Her biggest priority was that she and the children would be able to stay at the house and in the same neighborhood. Here she knew all people, one couple with children in the same class as her oldest often offered to pick up her children from school and from common activities of their children. Emilia was thankful. She wanted her children to have such a normal situation as possible especially when everything around them had changes a lot.

The feeling of not working

Emilia was unable to work, and she really missed the social life with her colleagues at work. Many of her colleagues were her friends, and she missed the chatting and the coffee breaks with them. She missed to talk about normal things, like daily family problems or the children. Now, she was home alone in a quiet and empty house, and the unstoppable thoughts and anxiety messing with her head. Sometimes she spent time with one of her colleagues Sofie, but it was not the same as before. Without her job, and without the possibility to accomplish something every day, Emilia felt very useless and sad.

After almost a year, Emilia was stronger both physically and mentally in between the treatments. She felt like working part time and asked about what possibilities she had, but it took very long time before she even got an answer. She had heard about something called preventive sickness allowance, but the officer at the Försäkringskassan was not too

overwhelmed about the idea and thought some other solutions were better. If Emilia was to go back to work, the work tasks might have to change and be adapted to her personal situation, and those possibilities were limited. After the meeting with the officer she chose to stay at home instead of trying the preventive sickness allowance, because economically she had to be sure to get most financial compensation as possible. The hospital round trips had cost her more than she thought, and very soon the New Year entered and then it was time to pay the new high-cost prevention for her medicines.

Can life return to normal?

Emilia's body responded well to the treatments. She was unsure about the final result, if she ever would be able to go back to the life she once had, but the doctors were positive. They told her they believed in her, and that she soon could be medically cured. Even though the results this far was positive Emilia had a hard time trusting them. Every step in the right direction was a relief for a moment, but the next day she found something else to worry about. Mentally, it was like a never-ending rollercoaster. Sometimes she let go of the fear, the tears, treatments, waiting times, and worries, phone calls. It was hard and painful, but necessary. She tried to imagine the life before the diagnosis came into her life, but it was impossible.

Sometimes Emilia felt lost in the system. The contact nurses and the therapists had been great support throughout the process, and had also helped her out with practical issues. However, it would have been preferable to have someone who had a holistic picture of her process, who had followed her and assisted her since the beginning. A person who could coordinate all different needs and connected the loose threads. Very often Emilia had to control and customize her own process in terms of papers and needs, and remember dates and medicines that she had been given earlier.

Medically cured

The 1st of July Emilia was declared medically cured. The cancer was gone and the treatment process was finally over. The happiness had no limits, and she called her relatives to tell the great news. Now, she was free to continue her life! But, all of a sudden she felt totally lost. Her life had for the past year been all about medical appointments and treatments, meetings and a struggle in order to be able to go through the next week. Now there was nothing.

Back to work?

Since Emilia was employed temporary the time before her sick leave, it was not completely sure that she could come back to the same work again. However, there was an opening, a temporary position of 50%, which she would be able to manage. She got 50% salary and about 30% sickness allowance from Försäkringskassan. Emilia started to work again. Her manager had been able to make some changes to her work tasks, and they agreed to the work tasks after some meetings. However, she felt like a burden to the colleagues, more than an asset since the changes also affected some of her colleagues and their schedules. She tried to adapt to the old life again, but at the same time she also realized how hard it was not to work more than she was supposed to. Work was her way out of the old and sick life she had been living for the past year.

After three months Emilia started to feel pain in her back and hips, and she started to get worried. She called the hospital and scheduled an appointment. The tests showed nothing special, and she realized it probably was complications from the treatment process and chemotherapy. The doctors recommend her to slow down and catch up with her personal life, but she could not relax and instead she did the opposite. She got an offer to increase her work

percentage, and she decided in consent with Försäkringskassan that she would increase her workload to 70%. She wanted to be back at work, but at the same time she was worried about her own health. Before Emilia got sick she had a hard time handling stressful situation, and now it was even harder. This affected her greatly in her way back to life, and it took longer than she expected. In November the situation was unbearable. She fell without anyone catching her.

The aftermath

Emilia was back where she had been 6 month ago, at home, alone. It felt as a failure to her, not being able to work. She was cured now, why was it so hard to get back to a normal life? The doctor gave her the diagnosis fatigue syndrome. Emilia felt she could not meet the high expectations made from society. She had no strength to stay positive or perform even the easiest of tasks. When she had sent her children off to school and daycare, she herself often went back to bed and cried. Emilia got a new officer at Försäkringskassan; a lady that seemed very kind and professional. In addition, now when she was finally medically cured, there was no apparent connection between the cancer diagnosis and the fatigue. The assessments were based on her ability to work, given the present circumstances, although the cancer was not taken into consideration.

After some time, the officer called to tell Emilia that she had analyzed her situation and encountered a problem. She wondered if Emilia had been registered and applying for jobs? Emilia could not really understand and asked what she meant. The officer continued and explained that because Emilia did not have a full-time employment, she wanted to be registered as a job applicant as well. If she had a 100 % level of occupancy even if she just worked of 70% she had protected her old income as a base for assessment. Since she was not registered at AFW for 20% she had now a new income that was the 70 % employment and that was what the new base for assessment of SA. This is illustrated in the Figure 4.1 below. Emilia did not knew what to say...

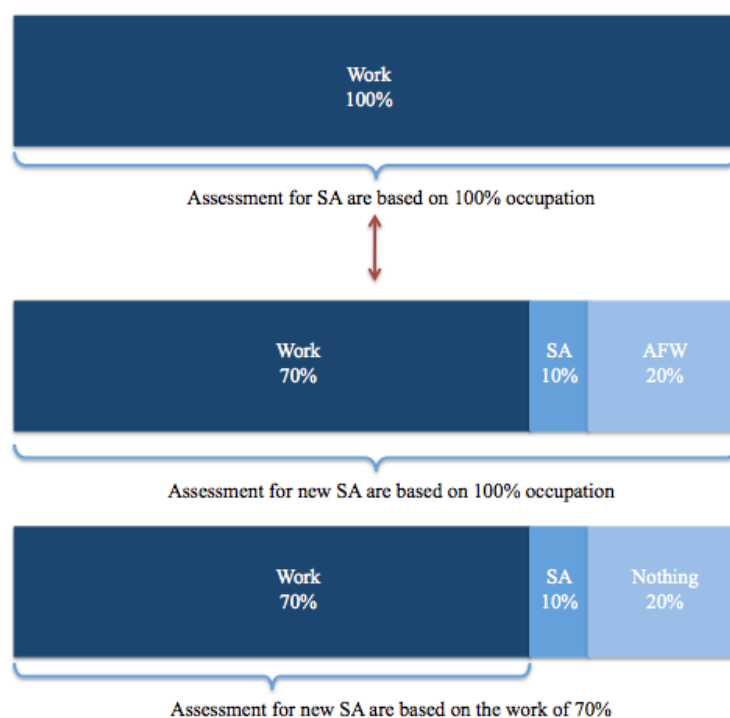


Figure 4.1 illustrates the different level of occupancy that SA has as a base of assessment and financial compensation.

As of today Emilia is still at home waiting for a plastic surgery, and a new breast. This will require new sick leave time from work. She tries to find strength and happiness, but it is hard. The weeks when the children are at their dad's, Emilia mostly watch TV, and she also tries to apply for some suitable work. Sometimes she takes a walk and dreams about doing something fun with her children. Maybe go to an amusement park, but very quickly she realizes she has no money for that. Who knows when Emilia can be able to work again? She attends rehabilitation and talks to a therapist at the primary care center. Most of the time she tries to find herself, who she is now, and how she can get back to life. Nobody knows, and neither does Emilia.

4.3 ORGANIZATIONAL CHALLENGES

There are always circumstances and challenges for an organization to find the balance between satisfying the customer, and operating efficiently. It becomes further complicated when the operations are financed by tax revenues, the decisions are made at a political level and the customers are the taxpayers. The following section present the organisational structure and current situation for the area of cancer within Försäkringskassan and the healthcare sector. The section also identifies organisational challenging areas in need of improvement. The data collection is based on information from interviews and meetings with people in the field and conferences connected to social insurance and health care in public sector.

4.3.1 FÖRSÄKRINGSKASSAN

Försäkringskassan as a government agency has the mission to meet human needs in specific situations such as reduced ability to work following from example a cancer diagnosis. The assessment and examination in order to get financial help is made by officers at the local offices with diagnoses and medical certificates as assessment materials. The officers are working locally with patients in the area to offer a personalized customer interaction. Försäkringskassan has the mandate to coordinate resources for the possibility to help an individual on sick leave payment to return to work. (Försäkringskassan, 2014)

The work of administrator performs in the Social Insurance can be assumed to belong to the group of qualified services. Qualified services can be regarded as labor intensive and it contains in large extent judgment and decision from the administrator. Risks must be constantly weighed against opportunities and many stakeholders are often involved in the evaluation process. (Tyrstrup, 2014) The regulatory framework for Försäkringskassan is based on a number of laws from §Socialbalken, which assessments must be within. The administrators never question whether an individual is sick, but do the assessment only on reduced work ability based on the evidence available. Day 1-90 impaired work on the user's regular duties is assessed. Day 91-180 assessment is based on whether the user would be able to perform other tasks on the current workplace. After day 180 impaired work is based on the ability to perform any job at the market.

Today, there are different perceptions of the degree of flexibility that administrators have. Some believe that there is relatively much opportunity for flexibility to find the most suitable individual solution for a client, which is in need of support and financial help, but that you

can never go outside the rules. Others believe, however, that the law and the regulations are quite strict, leaving little leeway for flexibility and individual adaptation of the person's judgments.

Cancer diagnosis is considered a serious disease, and all the respondents maintain that most cases are fairly simple assessments for Försäkringskassan where patients often receive full sickness allowance during this period. The complexity often arises at a later state when treatment can be considered completed and return to work and subsequent rehabilitation is assessed. Cancer diagnosis has then no longer any connection to new complications, such as mental illness or chronic fatigue syndrome that often arise as an aftermath reaction. In order to create the best situation possible at this stage, it is important to have a closer communication than before between users, officers, job placement and physician. This is to be able to protect the patient's sickness allowance and jointly develop a sustainable position and return to everyday life. For example, in case of a return to work at 50 percent, it is important for the user to be registered as searching for employment at the remaining 50 percent for a 100 percent employment secured for any additional sick leave that may be relevant. Today this is something that is not always clear to the users.

Qualified services can also be regarded as mentally and socially intensive where reception plays a major role. (Tyrstrup, 2014) The response among administrators and users can today be very different from case to case. Some administrators have easier to deal with difficult life situations and can become a close support for one user whereas others administrators have difficult to convey understanding and have a feeling for the users' life situations. The administrators are today receiving no specific training in handling sensitive life situations and conversations with people that suffers from cancer. Today administrators also handle all kinds of diagnoses and average wrists 70 people at once. Since the diagnosis, conditions and problems today have great variation from one user to another, it is also difficult to have an overall knowledge of a specific life situation. Initiatives have been taken to start a small local network where one or a few administrators only take care of sickness allowance as a result of a tumor diagnosis. This is often pilot projects and has been practiced at few places in the country.

Today there also is a problem with the sometimes-negative images linked to Försäkringskassan, often created by writings from media. Administrators often face prejudices from users that sometimes makes it difficult to create a good relationship and work together towards a workable solution for the user. Many users also expressed directly to the administrator that they had an image of the authority that is not at all agreed with reality. This gap is illustrated in the Figure 4.2 from the SERVQUAL model. After a personal meeting with his or her administrator, the users got a different picture of the situation but also a greater understanding that administrators actually are people who want to assist the user in question.

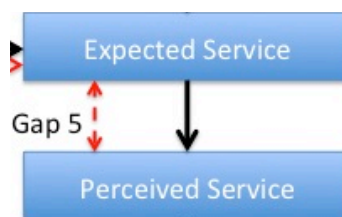


Figure 4.2 illustrates the gap that sometimes arises between expectations and the reality.

The majority of interviewed people believe that today there is too little concrete information about social insurance and an individual's possible future contact at some point in their lifetime.

Several officers also hope to make the rules easier to both understand and handle for the users.

Hartman described during SVEUS conference (2014) that clear practical information is today missing from Försäkringskassan about the most basic activities that user need to know with the interaction with Försäkringskassan. Half of the calls to customer service is about, when to expect the economic support to enter the bank account and how to do with the paperwork during the whole process.

4.3.2 HEALTH CARE

The challenges of cancer care right now face is primary a need of more resources for rehabilitation and possible return to work for patients. Currently there is no good rehabilitation system cancer patients can use and there is neither an arena to meet with potential employees or people in the same situation. It is important to try to find a functioning format of the return to work, especially for people who are treated for a long time and that the health care have to take responsibility and participate in the process.

Another challenge for healthcare is the stress factor as it means getting a cancer diagnosis. For many patients the period of treatment is influenced of negative and stressful thoughts that are often are related to anxiety, practical and economical problems. Sources believe that more time is needed with a counselor at the hospital for early mental processing. For patients who are living with a meager economy the entrance of another period in order to reach to the high-cost limitation of medicines and medical travel becomes sometimes also a concern. It is of common opinion that most doctors today are trying to help as many patients as possible so no one never have to wait to buy medications and thus get no treatment due to financial barriers.

Within the care of cancer, lead times have for a long time been in focus, especially the time between the first detection of something to the receiving of a diagnosis. Today, depending on the situation a patient might have to wait over a month to get your diagnosis determined. Reimers (2014) writes that the average waiting time to receive a cancer diagnosis is 35 days and for breast cancer. For colorectal cancer are waiting time in average 45 days. During the summer the longest waiting times arise which creates problems when the cancer does not take vacation or can be scheduled after a hospital's capacity.

The introduction of contact nurses at many places in the country has in the recent years facilitated the handling of information for nurses. Since every nurse takes care of specific patients creates greater security for both patient and nurse when the surrounding information is known and not need to be repeated. The introduction of the contact nurses also created a greater patient safety and an opportunity to be able to see the cancer process in more detail from a patient perspective. By having special nurses who could answer most questions it also released time from other professionals. The introduction of the new function also aims to provide shorter lead times and more efficient patient processes.

In health care there is also discussions around an improved and more standardized writing of certificates for sick leave. Today doctor writes certificates and it requires usually little contact with Försäkringskassan for further follow-up or clarification. Försäkringskassan sometimes

experience, however, that certificates are of various kinds, from various departments and levels, which complicates the evaluation process in the next step for the patient.

4.3.3 INTERACTION BETWEEN FÖRSÄKRINGSKASSAN AND HEALTH CARE

The most difficult challenge in the public sector is today to create a coherent system, which ensures greater security and value to patients. Ownership of and in particular the development of activities that involve many different stakeholders is currently unclear. Around the project with PSA healthcare, Försäkringskassan and patients experience a positive attitude and an opportunity to improve conditions for patients. At the same time more information and easier handling is needed for further development.

Who is responsible for this are not clear, nor decided. Försäkringskassan handles the sick leave process and assessments for the method's potential application of specific patient. Health care is responsible for the certificates, which are essential in order to apply the method and have interest in the patient's well being, both during and after medical treatment. The patient is responsible for the execution and practical handling of the method. The employer is responsible for the structure and opportunities at the workplace. Socialstyrelsen has responsibility in the regulatory guidelines and it's ease of use. Who will be responsible for further development and dissemination of information is therefore not obvious. Rehabilitation of cancer patients is also an activity, which involves all parties and stakeholders. Even here there are uncertainties concerning the possibilities and prospects for the area.

The problem today is also a difference around the interests and consequences of actions for each business. Sometimes there are areas which both social insurance and health care is involved in but where there are conflicts of interest. Doctors issue sick listings today but health care has no financial responsibility for the number of certificates. Försäkringskassan is considering medical reports are strong guidelines for the assessments and therefore sick leave assessment are made based on the information on the certificates. The lack of common rules and guidelines mean that the conflict is difficult to manage.

Another problem with the fragmented system is that there neither is a common medical record or ability to see a patient's journey over time today. The units have systems that are running separately but there are no joint systems where the patient's journey can be mapped or viewed by both parties. There neither is any standardized way of transfer information to Försäkringskassan from the health care in order to facilitate the assessment for the officers. The lack of common language and poor contact surfaces put the patient in the middle where he or she are the only one with the whole picture of his or her process.

4.4 INTERESTING INITIATIVES

In the recent past, initiatives have been taken both regionally and locally in various places in the country to increase collaboration between authorities, Försäkringskassan and the health care sector. There is still no uniform national structure to promote interaction. The following section aims to present a few pilot project within Sweden which received both positive reviews but also have challenges to solve to be able to become leading method in the field. The section also present a model for rehabilitation with high impact used in United Kingdom. The data collection is based on field trips, interviews with people active in the projects and documented information around the initiatives.

4.4.1 PREVENTIVE SICKNESS ALLOWANCE

Ulf Hallgärde is the project manager for improvements of the SA process and rehabilitation guarantee in Region Skåne, and he is managing the question of adequate SA where the diagnosis itself not need to be the reason and basis for SA but rather the treatment periods. Today it is the diagnosis that in most is the substrate for the judgment. Treatment is often episodic and enables work on days when you do not get treatment and feel capacity to perform tasks at work. Preventive sickness allowance (PSA) implies that a patient is in trust to report those days to Försäkringskassan when he or she was on treatment or was not strong enough to work. The patient then get economic compensation for those days he or she reported away from work with the same rules as normal SA. PSA is the output of the project on improved sickness allowance process and rehabilitation guarantee which patients have experienced as positive. The aim with the method is to maintain patients social and work-rooted professional identity. The SA system is illustrated in the Figure 4.3 below.

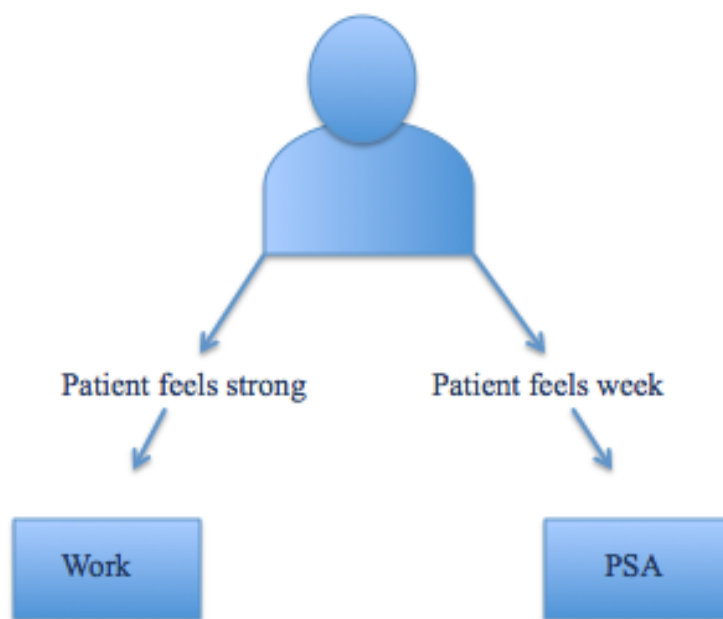


Figure 4.3 illustrates the choices a person has when using PSA

A study of Brundin et. al, 2014 compared to the return to work (RTW) for women with possibility to receive preventive sickness allowance. The study present that people with the same cancer diagnosis, in this case women with breast cancer who had been to the two different types of sickness allowance has a different number of sickness allowance days. A person who has gone on PSA, had in average 90 days with compensation from Försäkringskassan while a person who had SA, in average had 140. The study period was one year from 2013-05-01 until 2014-04-30. The age distribution was similar in the the groups.

Hallgärde also says that the purpose of the PSA is to get a greater flexibility for patients and to prevent the frequent subsequent depressions that long absence from work and processing of a cancer treatment usually involves. The key might be to never really let go of their "normal" life for an easier RTW. The complexity is now about the regulatory framework and the basis for being able to accept PSA for a patient is currently difficult for administrators which generates long wait for the patient, today about 1 month. The waiting period forces people sometimes to avoid using the method and instead quickly get a decision of regular SA and faster economic compensation.

The women that participated in the study reported well being and flexibility in their life when they could make decision upon their own capacity, to work when they felt strong enough and at the same time concentrate on getting well during the treatment process. The writers also emphasizes the importance of avoid unnecessary concern from patients, decisions and payments has to be performed without delay. (Brundin et. al, 2014)

Within Försäkringskassan there are fragmented opinions about PSA. Some embrace the method, and express that PSA is something that more patients could benefit from. Those people means that PSA today are underutilized and could absolutely be practiced both during and after treatment for patients with cancer. Today persons with diabetes and people that try to get free from addiction to drugs with good results mostly try the method. Some officers see PSA as a possible solution after completion of cancer treatment and in association with rehabilitation and return to work. The person describes, however, that they has never come into contact with a patient who would be able to work some days during the period of illness. The person says that it could probably apply it to cancer diagnosis but would be very individual.

Hallgärde believes that a simpler regulatory framework of the law would be needed, as well as more information to both administrators and patients about the possibilities and the impact on health insurance options. Försäkringskassan have the same opinion, the frameworks for the officers need to be easier to use and handle but also that more information is needed for the health care about the method. Hallgärde points out that for ability to succeed in operate the question and implement on a national level would be needed to reach out to more patient organizations which can operate under pressure. Moreover, there would also be a need to have a systematic development process including health care, Försäkringskassan and patients.

4.4.2 DISA

The DISA-project was a cooperation project aiming to create higher individual value for patients with a cancer diagnosis and a more efficient cancer treatment process run by the Insurance Fund in Kristianstad, the Central Hospital in Kristianstad and the organization Fenix (the unit of mental illness support and cancer rehabilitation). These three organizations worked in collaboration with each other in order to create higher value for their individual cancer patients via early rehabilitation possibilities. (Regionalt Cancercentrum Syd, 2013) The project was directed to both patients under treatment but also those who suffered suites from a cancer diagnosis. Besides the primary aim, Försäkringskassan hoped to improve the organization's reputation as an indirect effect of the project.

The investment in the project was 3.1 million sek, where the government funded 50% of the entire investment. The project started of with patient interviews where they could express their thoughts about the cancer process as a whole, in terms of psychological aspects, experiences with the Insurance Fund, rehabilitation and the healthcare process. It showed that patients were anxious when getting the diagnosis and right after the treatment process ended. Some patients also said that the contact with the Insurance Fund worried them, and that the meetings with them could vary a lot. It also showed that the patients barely had any expectations regarding the existing rehabilitations possibilities. The generated information became the major input into the project, and from this information a model for improvement of handling cancer patients started to grow. (Regionalt Cancercentrum Syd, 2013)

"Cancer Rehabilitation aims to prevent and reduce the physical, psychological, social and spiritual effects of cancer and its treatment. Rehabilitation efforts will provide patient and family support and the ability to live the best life as possible. " (Nationella vårdprogrammet, 2014) A collaboration started then to create a better rehabilitation process with health units, insurance office, employment agency, municipality and patient organizations as participants.

The model of handling cancer patients is now in use and involves several steps in order to create higher value for the individual cancer patient. Försäkringskassan has educated two officers in the basic fundamentals of the diagnosis of cancer. The education has created an awareness of the circumstances and challenges a cancer patient faces when receiving and living with the diagnosis. Treatments, physical conditions and physiological challenges all affect a patient's life. Therefore these officers can take more into consideration when determining the need of sick leave for an individual. After the meeting with Försäkringskassan each patient is offered a rehabilitation call for establish the contact. (Regionalt Cancercentrum Syd, 2013)

A rehab conversation takes about 1 hour and relatives are always welcome to participate in the talks. Important point out is that it is the patient who decides. The aim is to create rehabilitation in preventive purpose, to repeat information to the patient, encouraging physical activity and reach out with doing something little all the time is significant. After the treatments are over they will get in contact with a rehabilitation coordinator in order to get a rehabilitation plan. The rehabilitation plan is created by a joint assessment of the situation with the insurance fund, employers and rehab coordinator. The Rehab coordinator are then doing rehab plan with the patient and besides have continuous contact with the person. Rehabilitation has no timetable set but is adapted as the process progresses.

At a visit to Kristianstad Hospital, involved in the project expressed that the project created good internal communication between clinics and departments, and between healthcare and social insurance. This has resulted in a better overview of the entire life event for cancer patients and a more individual system. Participants in the project group also feel that they have a knowledge increase among employees in both healthcare and social insurance office. Administrators had the opportunity to talk with contact nurses giving an increased understanding and confidence for conversations with cancer patients and medical staff had increased transparency in the social insurance approach. Although contact between businesses has been improved. The coordinator sometimes makes preventive call a specified officer to advise that it may not be an optimal time to contact a specific patient right now.

The difficulty has consisted of making it hard to make a distinction for which rehab to be linked into which the clinic. These borders are diffuse and there is no clear division. Involved emphasizes that when a system or project is under construction, it is important to be able to be flexible with working methods. It has also sometimes been a problem on how much material is extradited around patients' medical records to administrators. The solution has to be able to share what is essential for the specific situation and if increased value to be achieved otherwise the information has been kept for each unit. The difficulties right now also includes how to anchor the project in the organizations and possibly be able to scale up and transfer to other areas or geographic regions. The project is currently still very depending on the persons involved and project participants are those with the most knowledge about the process.

4.4.3 MAGGIES CENTER

Maggie's Centers are caring centers with drop-in for the after-treatment of cancer patients. The treatments are not said to be a replacement for regular cancer therapy at hospitals, but rather a support function providing a still environment. Patients can feel comfortable and get information about practical issues, and get the possibility to communicate with others. Qualified experts work continuously with emotional support and therapy groups. The locations of the centers are always close to the regular cancer hospitals. They are owned and run by the Scottish registered charity and free of charge. The first center opened in 1996 in Edinburgh, and now there are 17 centers up running in UK, abroad and online. (Maggie's Centres, 2014)

Maggie's Centers are not only meant for the cancer patient, but for family and relatives too. The provided help tools and programs are there to support the affected people in the process, in order to help them find physical strength and emotional wellbeing. For example they provide classes of yoga, relaxation classes, and make-up sessions where patients can get physical help and information regarding how it is to live with a cancer diagnosis. The rooms in the centers are built without front desk, receptionists and waiting rooms in order to make it as welcoming as possible. In some cases these centers become like the patients' second home. The centers want the patients to keep on experiences the joy of living, instead of fearing the death. (Maggie's Centres, 2014)

4.5 MEASUREMENT OF RESULTS

Experience based design is gaining ever greater scope in the development of health care. At the same time it also raises the question of how performance should be measured. When the process and the development involve people it is hard to just practice quantitative measurement and statistics. To measure only numerical results also lose a bit of the purpose when a better life situation for patients often is the goal to achieve. The question of "how do you measure the improved wellbeing and value for patients in qualitative measures" is therefore something that needs to be discussed. This is illustrated in the Figure 4.4.

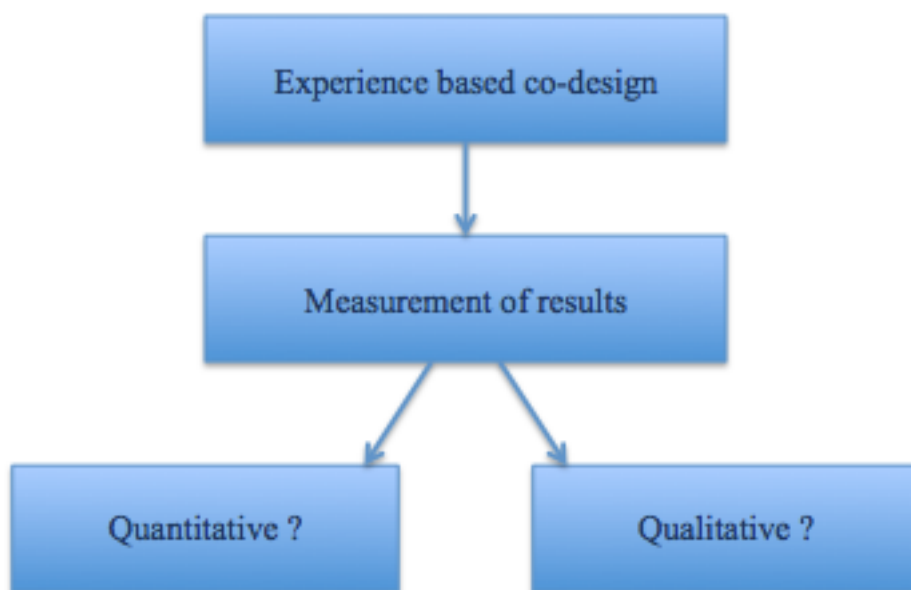


Figure 4.4 illustrates the complexity of what results to measure when using experience-based co-design as a method for organisational development

Difficulties also arises around the patients who gives their experiences today are not in the same situation in for example two years ahead in which these experiences possibly been harnessed and converted into enhanced actions in practice. Therefore, the same patients can not express whether the situation has been improved. The same problems exist for the patients who go through the improved process. They have not experienced the situation as it was before and have nothing to compare to.

DISA project faces at the moment a measurement problem. The projects time span was two years and is now in evaluation phase. The metrics, which first was used, was to measure if the number of long-term disability registered at Försäkringskassan had decreased in numbers after the introduction of rehabilitation method. This was however, demonstrated to be premature to measure since the time horizon was not long enough to provide reliable results. Discussions from the project participants are now on whether if it is possible to use groups of patients from other regions of the country to compare the situation with or without the introduction of rehabilitation methods. With the experience it would be comparable and provide an indication of how the difference in methods affect a patient's life situation.

5. ANALYSIS

The following chapter presents an analysis of the most important identified areas of improvement in the interaction between the patient, the healthcare organization, and the Försäkringskassan. The areas are the ones illustrated in Figure 5.1 below, previously presented in the theoretical framework. These were identified during the study, and will now be analyzed with help from the theory. The structure of the analysis will follow the structure of the theoretical framework, where the overall important focus is the life event of getting cancer, and the individual value of the patient. Firstly, important results from the Effective Scoping tool will be presented in order to gain more knowledge and insight in the different areas of improvement.

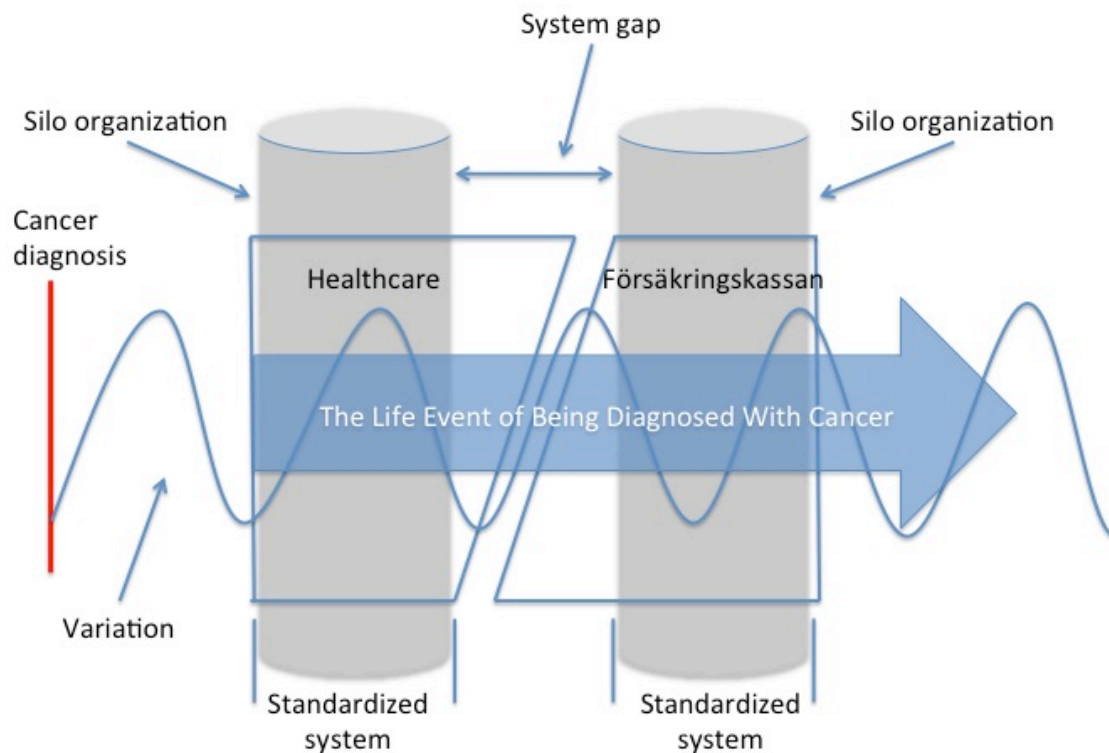


Figure 5.1 illustrates the most important areas of improvement in the process of the life event of a cancer patient

5.1 EFFECTIVE SCOPING

In the effective scoping all information and data collected from the interviews were clustered into groups answering the questions. The data was then analyzed and restructured if needed and the results of the work is presented in the Appendix III. The question 1 and 3 initiated the discussion about what the output of the process really is, and what requirements the users of this output demand. The results were as the Figure 5.2 below shows.

| OUTPUT | OUTPUT |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Q1. What is the output? Standardized solutions - Not too satisfied patients - Increased long-term sick leave % - Unemployment - Treated patients | Q3. What is required of the output from the user? Communicate Understanding Care, guidance Individual solutions and value See the life event |

Figure 5.2 shows the results of the 1st and the 3rd question of the Effective Scoping

The results from the effective scoping showed that the output from the process today is mostly standardized solutions with not too satisfied patients. This in turn could lead to increased long-term sick leave rates among the employees, because of tough circumstances to return to work and the life they had before being diagnosed with cancer. However, many patients said they have experienced high degree of healthcare quality, where they think that the actual healthcare treatment process medically was very well suited for them as individuals. The actual problem is more in the soft value surrounding the actual treatment processes, where the patients express needs more towards communication and understanding. They would value more individual solutions to get them back to life and work, and to see the whole life situation of being diagnosed with cancer.

Another important aspect to consider from the effective scoping was the matter of input to the system, and what is required by the input today. This is shown in the Figure 5.3 below.

| INPUT | INPUT |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------|
| Q8a. What are the inputs to the system? Variation such as: - The patients, in terms of their individual life situation - Patients' expectations - Försäkringskassan officers - The doctors' notes | Q9. What does the system require of the inputs? Standardized solutions Low variation No differences |

Figure 5.3 shows the results of the questions 8 and 9 in the Effective Scoping

The input to the system seems to be very much about variation, in all the different input parameters. The patients entering the systems have different backgrounds and life situations as they get diagnosed with cancer. Children, work, partner, or unemployed, it all matters to a person diagnosed with cancer. Also, the diagnosed patients will have different expectations of what to get or receive from the process. This causes variation to the inputs to the process. So do the differences in how the Försäkringskassan officers handle their work when diagnosing patients, and the differences in how the doctors write the diagnosis and the papers to the Försäkringskassan. If then the right side of the Figure 5.3 is analyzed the system of today does not quite support the incoming variation that seem to be the case. The system today requires standardized solutions where the input should be of lowest variation possible. No differences are really considered when handling the patients in this matter, because the system may not be structured in the most suitable way in order to handle it.

This valuable information will now be further analyzed in the analysis below, and the analysis will follow the structure of the Figure 5.1 above, starting with the aspect of increasing the individual value for the cancer patients.

5.2 INCREASE THE INDIVIDUAL VALUE

The change of focus of the overall caring process, to see the life event of getting a cancer diagnosis, is a big change for the public sector organization. The picture above illustrates the situation of many cancer patients in the system today. The blue arrow illustrates that the patients go through different stages and treatments, but without any connections between the activities. The focus changes depending on what activity is performed, and this is what needs to be considered when the overall focus of the process is the patient and the life event. Both the healthcare organization and the Försäkringskassan value the new focus of the process to be the individual patient, and to increase the individual value.

The literature considers seeing the organizations as value creating service providers, since it harmonizes with focusing on the life event of an individual patient. Since the service could include many different components provided by many different actors, the challenge here could be to start aiming towards the same goal. The goal becomes seeing the possibilities of creating individual value for the individual patient. The system could possibly not be able to perform these service components independently of each other and hope to get a good result, because they might be dependent and could in the worst scenario therefore counteract, and give bad results. Expressed by Emilia in the empirical study, she thought it was a need for more individual solutions and adaptations to her personal situation. Since the patient is the important focus of the services, an organizational structure based on the specific need of a patient will enable the system to work in the most efficient ways in terms of value creating services. Proceeding to work as the system is structured today around organizational specialties could possibly prevent the organizations from cooperating in value creating services since the boundaries between the divisions could be hard to win. The literature talks about co-production or co-creation of services, where the aim is to involve the patient and produce the service together. In this case it is a matter of involving the patient in the creation of the service, and consider the individual need even further than trying to create a service designed to fit patients overall. It can be compared with trying to overcome the Gap 1 in the Figure 5.4 below, where there is a difference in the expectations of a patient, and the understanding of the service provider.

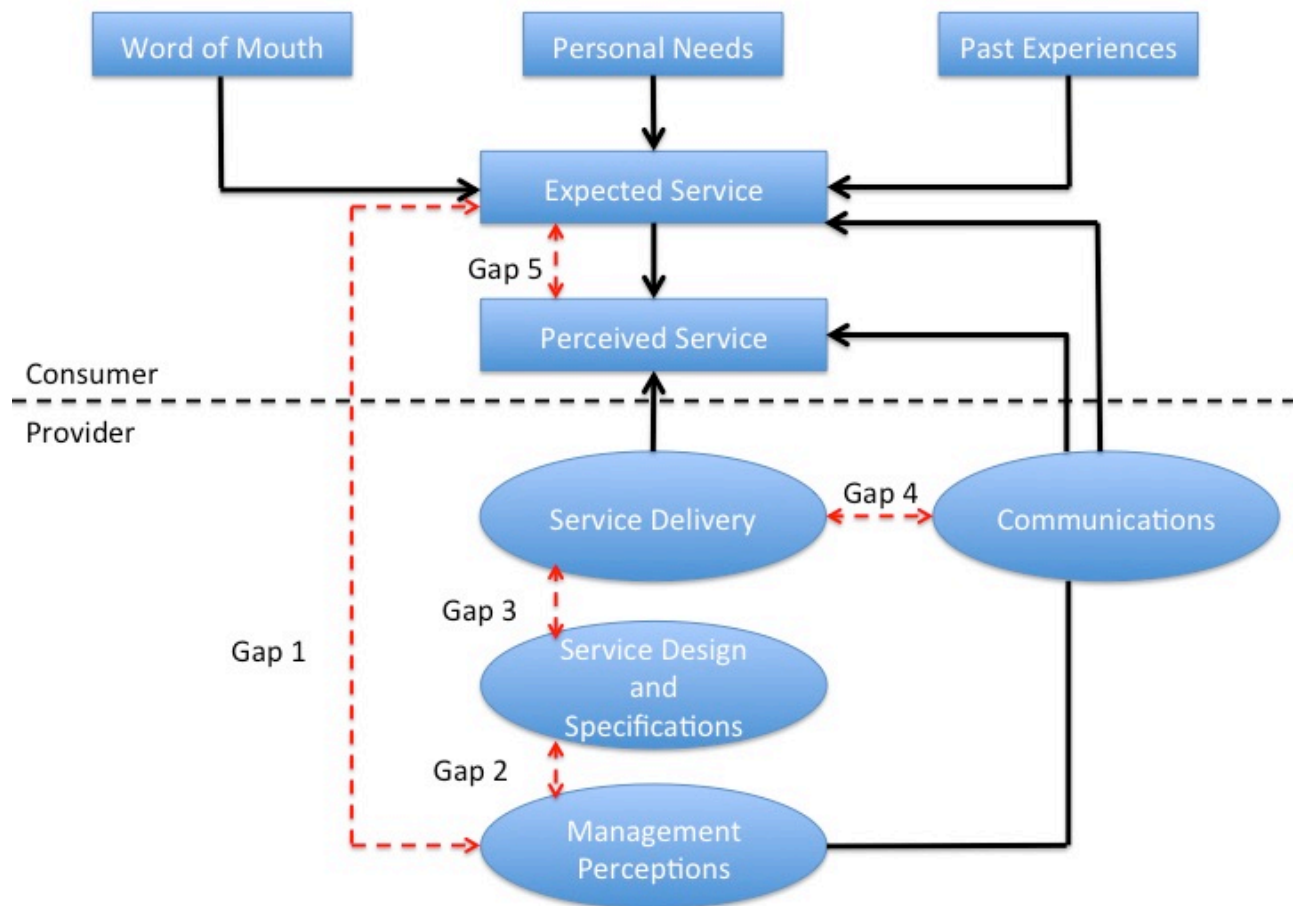


Figure 5.4 illustrates the different possible gaps that could occur between the provider of a service, and the service consumer.

If seeing to the situation of Emilia, she could have been included in the design of her own caring process, which could have helped bridging the problem of the system understanding her needs, and her own expectations. By focusing on and understanding her individual situations and expectations, and identifying her needs and thoughts, the services could have been focusing very clearly on her. It becomes a situation where there is a matter of not having the patient as a consumer of the already pre-produced service, but rather find the patient involved in the service production in order to approach the actual need. Having the patient consuming an already pre-designed service could most likely increase the risk of not satisfying the actual needs, and create the Gap 1 illustrated above. This could in turn increase the uncertainty and loss of patients along their way through the service system. Therefore, it becomes essential to involve the patients in the creation of the service as a co-producer. This could most likely increase the individual patient value, by decreasing the gap between the service provider's understanding of the situation, and the patient's expectations. It is important to realize that the overall focus of seeing the life event of a cancer diagnosis can be considered if the patient is a co-designer, because the patient has the best perception of what is needed in her or his personal situation.

5.2.1 THE ROLE OF THE PATIENT

When involving the patient as a co-producer, there is a matter of considering the role of the patient. If the system is seen as a value creating service system, and the patient is to be

included in the creation, the patient will no longer only consume a pre-designed service, but rather from the beginning of the service creation. The literature emphasizes the importance of the system to be prepared for the patients to be involved, and that they have adapted to the flexible way of working as it requires. However, in a co-production of a service it is of great importance to be aware of who is in power of the decision-making. Every patient is unique and individual, but at the same time there are rules and regulations guiding when making final decisions, and that is important for all actors involved to be aware of. Emotions and specific situations can occur and have a huge impact on the way humans handle and want to cross rules, and in this case the illustration below emphasizes the importance of informing and communicating what the services include and what guidelines there are. Therefore, the balance of consensus and agreements are essential to consider when co-producing with patients. Their needs and wants are the overall aim of the process, and the activities have to be within the set guidelines.

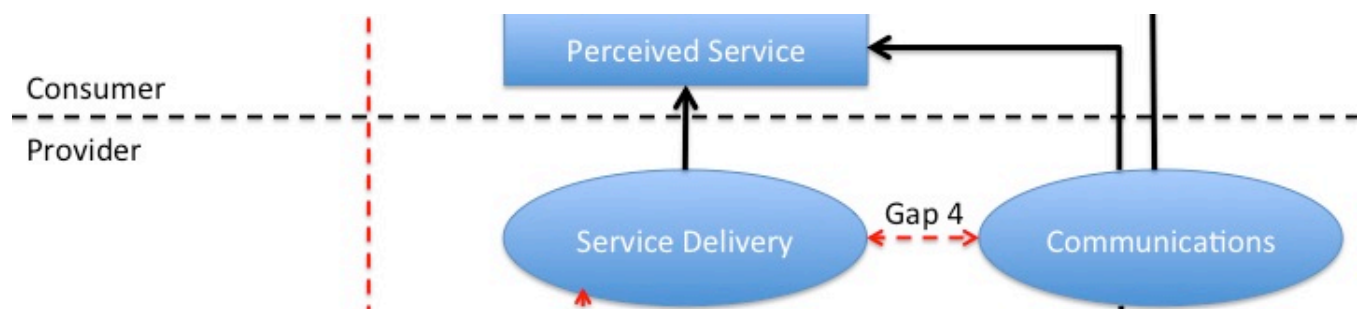


Figure 5.5 Illustrates the need of communicating what the service includes

As the Figure 5.5 illustrates it is important to communicate to the patients what the services include, and what the role of the patient is going to be. In the literature the Gap 4 occurs when the service provider poorly handles the communication channels, and the consumers do not get any information regarding what to expect. The perceived service could therefore differ from the service the consumer expected, and in the situation of when a patient is to be included throughout the entire process in order to determine and affect the individual choices of their personal situations, this gap is in need of consideration. If the patients could enter the process and know what to expect, and what is expected of them, the Gap 4 can possibly be reduced and the system will be able to increase the individual value for the patient.

Emilia was actively searching for valuable information from the first day she got her diagnosis, and this is possibly the situation for many other cancer patients as well. This indicates their natural interest in gaining knowledge of the situation. The literature discusses the increase of passive consumers, which does not seem to be the situation for many cancer patients, based on the conducted interviews. This opens up for a good opportunity of involving the patients in the process by providing them necessary information and describing their personal function in the process. As in the situation of Emilia, she could have known what to expect from the process in the future, and be involved in the design of her own process, and be aware of her involvement, and asked to help co-producing. As the literature says, this could help bridging the gap between the patient expectations and the perceived service even further, when the patient is included as a completely informed and aware co-producer.

When the patients are to be involved the literature emphasizes the importance for the public sector organizations to know who will perform the different services, and who is responsible for specific areas of services in the system. It could help enabling and make it easier to structure the service process, and therefore gain a clear picture of the service process. As the Emilia situation illustrated, the service process can sometimes be experienced by the patients

as confusing, because they might pass around between different actors, because the system itself might not be clearly structured. In Emilia's case she got confused and did not know where to go. Who is the service owner is a critical question to answer, and as the literature discusses it can be very challenging to answer in the case of dealing with patients. The life event of a cancer patient is not a process where the patient completes one step and goes over to the next step. Emilia had different processes going on simultaneously, and it was hard for her, and the system, to keep track of what is next.

5.2.2 PATIENT VARIATION

The blue arrow presented below in Figure 5.6 is the perspective focusing on the individual patient and the life event of getting diagnosed with cancer. The sinus curve starting before the blue arrow, and ends at the point where the arrow starts, presents the variation of the different patients getting diagnosed with cancer, in terms of their expectations of the services before entering the process. After Emilia got her cancer diagnosis she reacted as possibly many other patients in the same situation; she searched for information in order to gain knowledge about her situation, and also in order to know what to expect from the upcoming process.



Figure 5.6 illustrates the blue arrow as the life event of getting diagnosed with cancer, and the sinus curve presents the variation in patient expectations

Every patient is individual, and has different backgrounds and past experiences, and as the literature says this builds up a variation in expectations. Some patients might have been in contact with the system before, while others never even experienced it. As in the situation of Emilia, it might be lots of information to process before the actual treatment process has started. When seeing it as a value creating service process literature discusses the importance of being aware of how the service is expected by the consumer, and that the final expectations are based on what the consumer hears, knows, and thinks, but also how the provider succeeds in marketing and describing the service to the consumer, as illustrated above with the black arrows in Figure 5.4.

The life of a person in the middle of life differs from other people in the same age, but when being diagnosed with cancer they will be pushed into the same system and be cured in the same way. Some people have children, while others are singles. They might have relatives or family members in need of personal assistance. Some people might have financial problems or other psychological difficulties. Some individuals have work to attend, while others are unemployed. Some individuals are capable of a return to work without major difficulties after

cancer treatments, while others need help and support from care units. Patients' behavior, life situations, and needs are the input to the system where the public sector aims towards caring for all individuals, and find an individual solution depending on the different situations patients are in. It is not just the variety of patients that must be taken into consideration. Public sector, government, and healthcare can be counted as a labor-intensive industry where people are constantly involved in decision-making process and the creation of output. (Jones, 2013) It is therefore natural that some variation occurs due to personal differences. Today, the Försäkringskassan has unwanted variation, which is difficult to escape. In the majority of their work, each officer is responsible for the patient's assessments and may therefore differ slightly from one officer to another. The estimations claimed by the officers are also based on the medical certificates, and these certificates can vary in terms of clarity, form, and detail.

When a process involved people there will always be great variation in several parameters. The variation is difficult to avoid, but at the same time it is necessary to let people be individual. People in the middle of life have extremely different life situations. Here, it is important to highlight what the literature discusses, that the variation should not be eliminated, but rather handled in the most suitable way. The individual parameters can be identified, and estimated. Whether the person with cancer has four children and is a preschool teacher, or are a single woman in a consulting career, the system solutions should adapt to the situation with focus on the person's individual circumstances. All patients should be given the same opportunities for a good life situation before, during, and after treatment.

5.2.3 PATIENT EXPECTATIONS

The sinus curve within the blue arrow in Figure 5.1 can occur when the patient expectations differ from the perceived service, as illustrated as Gap 5 in the Figure 5.4. This gap is directly affected by the patient, but the literature argues that the gap can be largely affected by what the provider of the service does to communicate, illustrated as communication in the picture. This is because the provider affects both the expectations, and the perceived service at the same time. When Emilia entered her caring process her expectations of the process were based on different sources of information and previous experiences, affecting her final expectations, and not too much based on communication from the involved service providers of the system she was to enter.

The Försäkringskassan, as one of the service providers, has for the past years been, and still is, working with increasing the overall opinion of their services and how it works out for their patients, in order to decrease the Gap 5. Despite the improvement work, many patients still feel that they do not know what to expect from the contact with them, and many of the patients can at first be negatively set to the whole situation. The expectations of the Försäkringskassan services have shown to differ largely among the interviewed patients in this study. On the one hand, there are those patients that expect less than Försäkringskassan can offer. They expect that the Försäkringskassan officers will not be able to help out to customize personal solutions. Patients of this kind very often believe they cannot influence the situation at all, and that the rules are tight and only to follow. This has shown to result in fearing patients who are afraid of the contact with the Försäkringskassan, which can take time to overcome. The gap between the first expectations and the final experiences take time and valuable resources to bridge.

On the other hand, there are those patients who think the Försäkringskassan has more to offer than what they actually do. This kind of patients believe to get more than what they can, and at times it can be outside the guidelines. This is not possible for the Försäkringskassan to

meet, because then they would not be a legal secure system. These patients often question officers about why it is not possible to fulfill the demands and needs they have. This may include dissatisfaction regarding financial compensation, waiting for process times, and overall system regulations. Between these two illustrated patient groups is of course a whole range of other types of patients, but this illustrated the two extreme groups of patients.

As the literature discusses it might be beneficial in this situation to consider seeing the relationship between the Försäkringskassan and the patient as a small community of practice, where information and knowledge is shared cross-boundaries to the patient. This could help involving the patient, and become a structured way of communicating the necessary information, in order to bring the expected service values and the perceived service value closer. There could be a smaller unit at the Försäkringskassan having the overall responsibility for the cancer patients. This could also possibly help increasing the individual patient value since the individual need would be considered and becoming the main focus of the activity.

The healthcare organization does also trigger many different expectations among patients. When a patient has received a cancer diagnosis it is difficult to take in and process the situation. This drives different expectations, depending on if you are open and ready to process information. If the patient knows what to expect after reading the information, the response to upcoming events in the process tend to be smoother, because the gap between expected and perceived service value decreases. Waiting time creates anxiety, and patients have a tendency to tilt and mix information when you just got a diagnosis that turned upside down of the world. Uncertainty can also be increased if the patient does not know what to expect during the treatment process, and when the different treatments will occur on a timeline. Frequently asked questions may need to be repeated many times in order for the patient to process the information, which takes time and energy for both patients and professionals within the healthcare sector. This can however be minimized if the patient is informed about the different times and milestones.

Erroneous beliefs create frustration from both users and the system of care, which takes time and energy to overcome. These gaps could be overcome by increasing the confidence of patients by informing them, and find a suitable individual situation. To overcome and manage those expectations, it is important to find new ways to reach patients so that erroneous beliefs can be minimized and opportunities enhanced. The Försäkringskassan describes that within the framework and regulations to follow for assessment, that there is flexibility and opportunities that officer together with the user can use in order to find a suitable path for the specific patient's life situation.

5.2.4 THE IMPORTANCE OF INFORMATION

The variation in patient expectations seems to make it harder for the service provider to meet the needs of the patients. As discussed, there are several factors affecting the expected value, and these factors, or the factors affecting those factors, could be important to understand in order to decrease the variation in expectations. The literature argues that the right information given at the right point in time can help directing the expectations towards the actual service values.

By handing out information very early on in the process, the variation could possibly decrease before entering the actual treatment process, as the literature argues, and this could then result in a decreased input variation to the treatment process. The reduction in variation is illustrated

as the red dashed line in Figure 5.7 below. The patients could then be guided in the right direction of what to expect of the upcoming process. The purpose is therefore to provide a clear picture of what the patient can expect from both the healthcare organization and the Försäkringskassan. At the same time, literature argues that as important as it is to provide the information early on in the process, it is also very important to continuously hand out information at the right point in time. As seen in Emilia's situation, when was given the diagnosis and then there was a time where she had to wait before getting any new information or updates. This can cause uncertainty and anxiety as the theoretical framework highlights, and in Emilia's case that is what happened. The importance of continuously provide information can be seen as one of the services in the value creating service process, and this is illustrated as the black lines throughout the entire process in Figure 5.7 below.

It is also a matter of providing the right type of information every time information is provided. As argued in the theory, many patients are searching for information and while searching, several factors are affecting their ability and willingness to know what information is valuable and true, and what is not. In the beginning of Emilia's life event, she started to search the Internet for information, and it appeared to be lots of easily accessible information. As the literature says, the mood of the patient will affect what type of information is searched for, and the information found will affect the mood even more. The type of information available will also guide the patient in certain directions, and as the literature says information can be used to make critical decisions and therefore it is very important to not miss-lead or misguide the patient by providing the wrong type of information. Another aspect that could possibly be of importance for the service providers is when Emilia searched the Internet for information instead of getting or using information from the service providers. This is usually a sign of not enough information, as the literature also says. It could be generate problems if the patients need to go to other sources in order to find information.

Earlier, continuous, and improved information quality is argued to further decrease the expectation variation, and possibly the time and effort spent later on in the process to guide the patients towards the actual service value in other directions could decrease. By focusing the expectations in the right direction, the variation of the input into the caring system will decrease, and the system can handle every patient in a better way since less time and resources have to be focused on non-individual value.

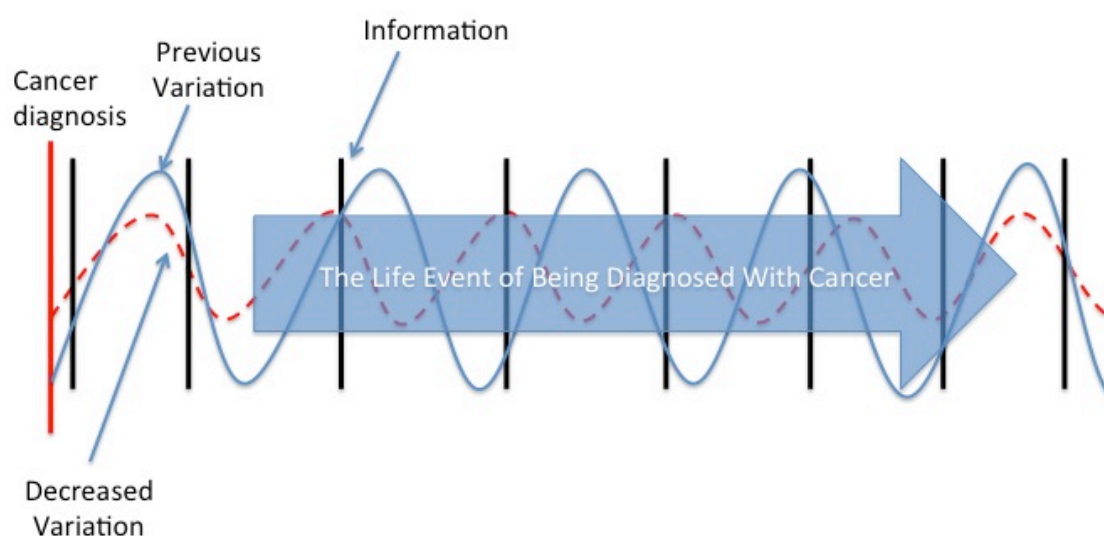


Figure 5.7 illustrates a decrease in variation amongst patient variation with improved information distribution.

Since treatment processes differ for every patient depending on the diagnosis, it could be difficult in the early stages to provide the correct information. However, in the Emilia situation it could have helped to hand out previously and frequently asked questions and thoughts by patients could be available in documented forms, to process whenever wanted. This could create a sense of control for the patients, and reduce uncertainty and anxiety as discussed in the literature, and they could see what the process would look like with waiting times, treatments, pain, or time at home. This information could also include other patient experiences in terms of how to get help for children or relatives, since the life event of getting diagnosed with cancer is argued to affect the entire surrounding of a patient. The literature argues about the importance of considering different kinds of information, and if Emilia would have decided something like a web-based platform could have been of interest, where the life event of getting cancer in midlife was divided into time periods, and where the answers to many common questions were posted. Here, it is of importance to understand what the patients want and need, in order for them to satisfy with the information available on this platform, as Jones (2013) also argues in his book about more information-seeking patients. Important is to provide the same information through different types of media in order to ensure that something is available to fit every patient.

As argued in the discussion about co-production of services, and the role of the involved actors, it is a matter who could be responsible for a web-based platform with the valuable information. It is a question of interest, and there might be a need for co-creation in order to provide the most suitable information gathered at the same platform. Emilia searched the Internet and realized that there were many different sources of information, and that there was not one main website provided by the service providers involved in her treatment process. As of today, the Försäkringskassan has their own one, while the healthcare process has their own one.

Information from the Försäkringskassan could be available on this shared information platform as well, in order to give patients valuable information before they get in contact or getting the first meeting with an officer. As for the previous discussion, frequently asked questions and answers could be available, and links to documents needed in the beginning of the process. This could help reduce the variation of the expectations of the Försäkringskassan further, and as mentioned in the situation of Emilia she would have needed information before her first meeting with the officer, because afterwards she realized her expectations were not close to the service she perceived. Answers to frequently asked questions like: When will I receive the payment? What does the process look like? What papers should be sent in? How does the system of sick leave work? By giving the patient valuable and early information from Försäkringskassan before the first personal meeting with them, the variation of expectations can be decreased before entering the service process, and argued by Emilia the quality of the first meeting can be increased. As the SERVQUAL model indicates and the literature argues, by including frequently asked questions throughout the cancer life event some system gaps could possibly be avoided, and patients can truthful and valuable information. As the services improve, the individual value of the patient is most likely to increase.

Försäkringskassan must meet the state laws and regulations, and due to their large gap between the expected service and the perceived service, they are actively working towards offering more flexibility in their delivery of services. For example, the PSA had a positive impact on patients' perceived quality of life and retention of professional identity. Also, the number of sick days compared to SA decreased, creating cost reductions for the Försäkringskassan. Even though they have got good results from this project, many patients

and officers have expressed their unawareness on this initiative. In order to be able to utilize this method more efficiently, more information is required by the patients, physicians, and the Försäkringskassan officers. It is also needed to anchor PSA in the business so that officers actually can offer and manage the method easily. Early information about the existing flexibility within the framework allows patients and the Försäkringskassan to easier meet the individual needs, and this will decrease frustration and fear.

5.2.5 INTEGRATION OF ACTORS

In the work of trying to connect the different services within the service process of creating individual patient value, one major challenge found is the system gap between the different actors, as illustrated in the Figure 5.8 below. A sustainable and cooperating system within the public sector is the creation of a knowledge sharing system or community, as argued in the literature, and to work with suitable and jointly developed tools and models in order to encourage knowledge sharing. As of today the individual organization, division or person has a rather well developed knowledge level, but in terms of helping or knowledge stewarding the system can sometimes seem to fail. In order to create shared knowledge, literature regarding communities of practice argues that jointly developed information and knowledge platforms and tools need to be anchored in the system. The involved actors should to be open for dialogue, and possibly create an open arena and environment of communication.

The creation of open communication can be made through forums, meetings, workshops, and gatherings, both formal and informal, as the literature says. As the empirical study shows, the healthcare organization and Försäkringskassan, as the DISA project, establish some initiatives. This project does also show the advantages of working cross-boundary, as the literature also argues. Establishment of cooperation between different organizations and different professions could increase the involvement of the patient. All of the knowledge creation and sharing initiatives should be documented and shared even further in the system to all actors involved, because, as the literature states, without knowledge sharing it is almost impossible to create a sustainable system. This could possibly be achieved through shared knowledge and information platforms such as knowledge databases, internet-based web portals, and information brochures, as many of the patients interviewed expressed need for.

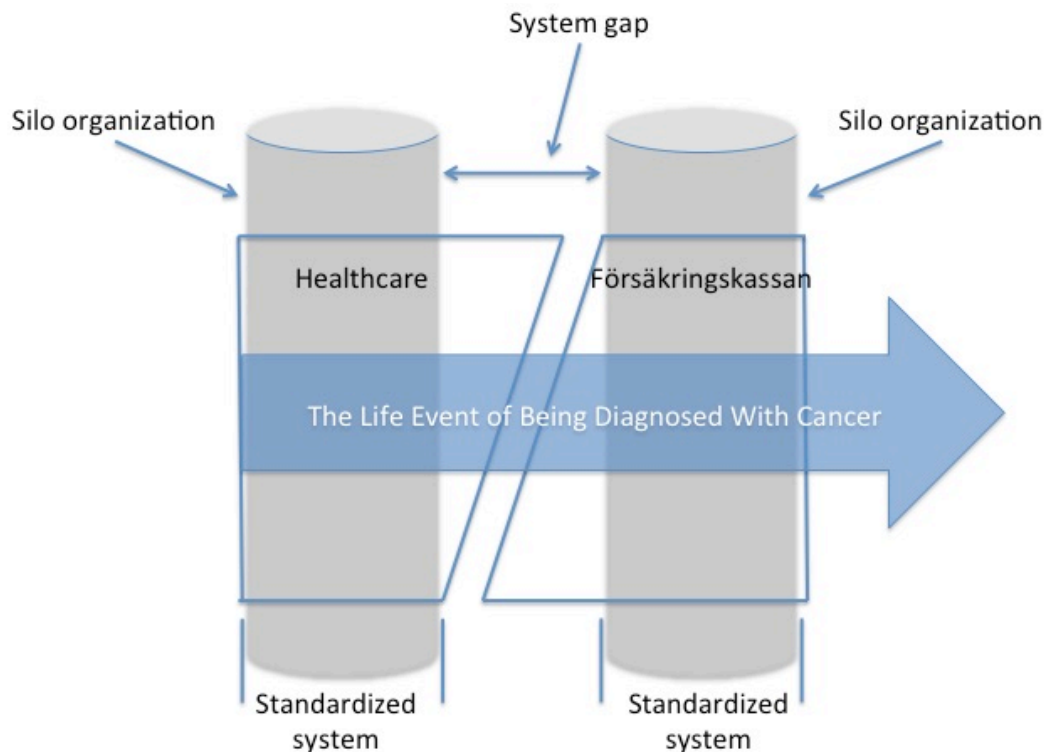


Figure 5.8 illustrates the system gap between the two silo organizations Healthcare and Försäkringskassan

In order to start acting towards integration all actors should consider what they can contribute with to the process, and start sharing their own experiences and knowledge. There is a need of coordinators coordinating the involved actors in order to point the system in the right direction. It could also be argued that there is a need for professional coordinators located at several places in the process, and as the project DISA showed they succeeded in coordinating the healthcare process, and also with connecting it to the Försäkringskassan. The project resulted in specifically two interesting outputs: firstly the satisfaction of the patients increased, and secondly the number of patients on long-term sick leave was not affected. On the one hand, since this project increased the overall satisfaction of the patients it indicates that the coordination and overall responsibility handled by the coordinator helped in terms of the psychological aspect. This could further be argued to have resulted in increased value for the patient, and the life situations as a whole. On the other hand, since the long-term sick leave was not affected nothing can be said about the actual physical results.

However, the project group in the DISA project argued that the measured results were conducted too soon after the project before any results could be expected. By developing common ways of measuring the results of such projects with help from the patients pointing out what to measure, the organizations can start focusing their resources and time in the right direction. As discussed in the empirical study, by law only health care employees are allowed to access patient journal, which could be a crucial factor when it comes to the questions of who could be responsible for an overall coordinator of the process, in order to have access to the most valuable information. One coordinator could be able to have the overall system picture, and by measuring results the system can figure out what processes that are dependent and affected by others, in order to enable the process to be managed in an easier way.

Another coordinator could be needed for the Försäkringskassan process, performed simultaneously as the healthcare process. As seen in the empirical study some of the

Försäkringskassan offices have already tried educating several officers specifically in the area of a cancer diagnosis. This way of educating officers showed positive results in the DISA project in terms of satisfaction among the patients. In order to reduce anxiety and uncertainty, which have shown to be two affecting parameters in the daily life of a cancer patients a coordinator is needed. The patients have indicated that the information is not enough, and by coordinating the information and knowledge the uncertainty and the anxiety can be decreased. Since only health care employees can access the patient journals, the officers at Försäkringskassan need to act as an information and knowledge-sharing unit. When no, or little information is shared the system creates gaps and language barriers between the different organizations, and unnecessary time is used in order to develop and work through problems that occur with the organization. As of today the officers have little information and understanding of the life-changing event a cancer patient is going through, and by educating the officers the gap between a patient's view and an officer's can be decreased. This will make the process easier and more patient oriented in terms of understanding the life event of a cancer patient, where no unnecessary explanations about the situation and possible side effects are needed.

5.3 SYSTEM IMPROVEMENTS

Today, the system of the healthcare organization and the Försäkringskassan could be argued to not be completely designed for handling the individual needs of patients diagnosed with cancer during midlife. This means that patients may struggle in order to manage the situation, and find solutions of specific issues that are important to them.

5.3.1 A SHARING SYSTEM

As of today, the involved actors in the public sector are internally divided or separated based on specializations or process roles, silos, with separated information systems and therefore they are not integrated. It results in differences in the spoken and written language, and also that the knowledge and the developed information are confined in these silos, as discussed in the literature. Another aspect found is that patients believe there is a lack of knowledge and information sharing in the public sector system, especially in the case of the Försäkringskassan. The patients argue that a holistic view of the whole life situation is not considered in terms of individual needs of customized information. It is a matter of seeing to the possibilities of increasing the individual value for a patient in the life event of getting diagnosed with cancer, rather than seeing it as different service providers trying to provide individual services to the patient, as the literatures also says. There are many different dependent sub-processes working concurrently when caring for a patient in the public sector, as seen in the story about Emilia, and therefore some restructuring might be needed in order for the involved actors to be able to provide valuable information and knowledge, in order to make the holistic view as valuable and well suited as possible. The restructuring of the organizations would merge their activities and as illustrated in the Figure 5.9 below, the gap between the two actors could decrease.

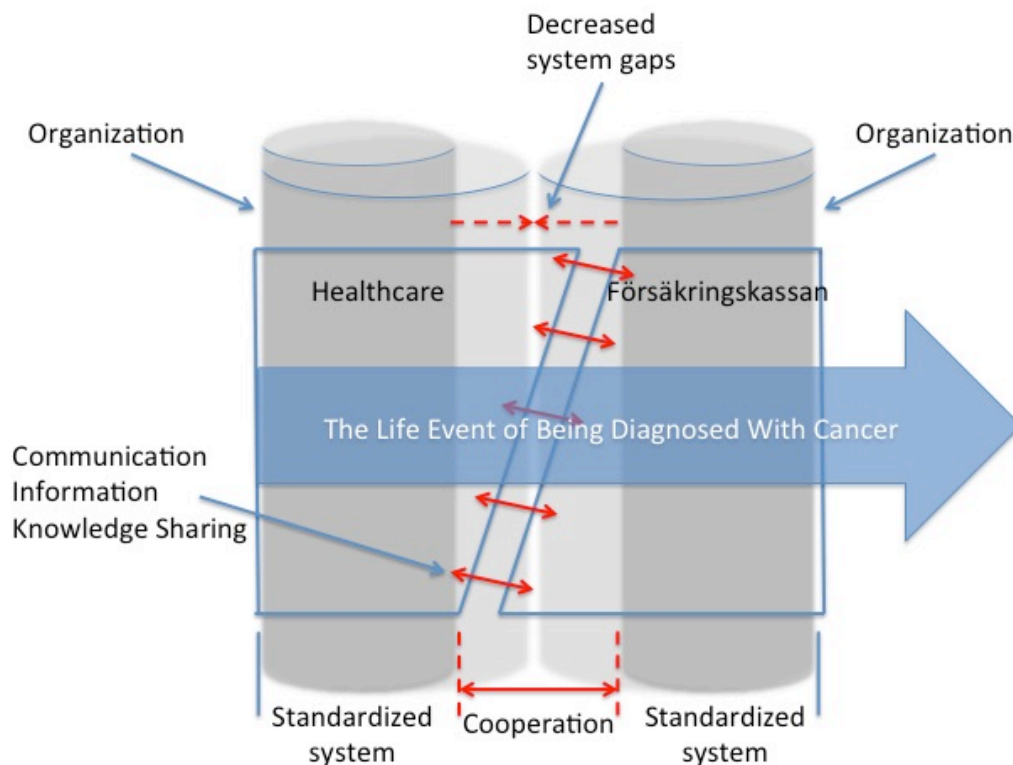


Figure 5.9 illustrates the decreased system gap and established cooperation between the Healthcare organization and the Försäkringskassan

To consider some sort of reorganization of the public sector knowledge sharing system could possibly be of interest for the system as a whole, because of right now the information within the system is not enough to satisfy all actors. Literature argues that moving from the isolated silo structure in the organizations to an open and encouraging environment cross-boundaries, will help increasing the sharing, and as seen in the DISA project this encouraged actors to cooperate, and benefit from it. All actors could engage in, and aim for a community focusing on the development and sharing of knowledge to all, and teach each other in order to increase the quality of the entire system, as the helping and knowledge-stewarding communities of practice describe. The system therefore needs to move towards integrated information systems and shared information platforms where information is to be well documented and written in a language understood by all actors. Also models where clear and informative guidelines will describe how to manage the models. This will enable them to create, share and gain new knowledge among each other. Cross-boundary integrations will link them together and teamwork will encourage and involve actors towards the same goals. They could be guided towards communicating in the same language and develop solutions in order to succeed, as illustrated as the red arrows in the Figure 5.9. It could also most likely increase and further encourage informal communication since, as Porter (2014) said, merge them together into one system where they experience the advantages of cooperating. The merged system is illustrated in the picture above.

5.3.2 EARLIER REHABILITATION

There seems to be a need for patient rehabilitation possibilities, declared both by the patients, the healthcare, and the Försäkringskassan. There seems to be a need for earlier patient rehabilitation possibilities, declared both by the patients, the healthcare, and the Försäkringskassan. They have expressed their individual need for a system of structured

activities, but there seems to be no structured way of dealing with the need as of today. The rehabilitation begins long after a cancer patient is getting the diagnosis, and when it finally starts there is not a very structured process guiding the patient through, in order to start preparing for coming back to the life they left behind before the cancer diagnosis. The healthcare organization and the Försäkringskassan do enter the process at different times in the life event of cancer patients, which could be argued to delay the work of rehabilitation.

After coming through the actual cancer treatment process many patients are released from the healthcare system and left to go home and start the journey back to the life they had before getting diagnosed with cancer. This could seem like a time where the patients are supposed to be happy and joyful and in some cases they are, but many patients are not finding the situation quite as easy to get through, as in the case with Emilia. She had many unanswered thoughts, and feelings of anxiety, uncertainty, loneliness, depression, and long-term sick leave. These are some of the results of this process ending. This time becomes the fight of their lives, and many patients expressed that they did not have the power to fight any longer, but needed to get help and support in order to get through. Feelings and thoughts gathered through the whole life event of getting cancer start popping up and becoming reality for the patients. To start with rehabilitation in this scenario seems to be too late, but rather begin the rehabilitation much earlier in order to get the patients to start processing their situation meanwhile they are in it. Patients need power and energy in order to get through a cancer treatment process, and rehabilitation should be there to help them. Argued by many patients is the need for the healthcare organization to stay longer in the process, in order for the patients to feel safe and able to call someone in case there are upcoming problems to handle. The following caring process might be handled by another instance of the healthcare organization, such as the primary care, but the communication should probably be through the original contact established in order not to confuse or lose the patient. This is illustrated in the Figure 5.10 in the end of this chapter. Literature argues that the anxiety and the uncertainty can affect the patient negatively, and it is arguable to say that it might decrease the possibilities of individual value, since this clearly is not what the patients might need.

As seen in the project of Maggie's centers, an organization with an extremely high patient focus, they have established places where patients and their relatives can come and process their situation as it is right now. It is a safe place where they are surrounded with other people in the same situation, and they can start coming there whenever they want after getting a diagnosis. These centers have resources and time to put into the rehabilitation of the patient, which creates a feeling of entirety of what can be done. They have classes and projects such as yoga and make up instructions, in which the patients can take place. The essence of the centers is to increase the value of the cancer life situation, and empower the patients of their own life situation in order to energize them to come out of the process with good personal results. The patients are free to come and go as they please, and they can customize their own programs in order to fit their needs in the best possible way. They are in charge of their own decisions, within the flexibility of the system.

One important aspect to consider regarding earlier rehabilitation is: How can the value of a cancer diagnosis life situation be increased? It is said in the conducted interviews in the empirical study that the rehabilitation starts the day the patient gets the diagnosis. Psychologically and physically the diagnosis hits the patient hard, and it is from this point very important that the patient know where to get the help needed. As of today the patient has long waiting time in the beginning of the process, and that can affect the patient negatively in terms of psychological instability and mental breakdowns. This results in increased weakness without focusing forward. In order to support the patient from the beginning and

psychologically start processing what is to come and how to get through it rehabilitation possibilities are needed. Therefore, there might be a need of both the healthcare organization and the Försäkringskassan to enter the process of the life event very early, in order to start working with the rehabilitation process from the beginning.

Since Maggie's centers get the financial support not from the public sector it is important to understand that a cancer treatment center within the public sector could possibly not be design the same. However, many ideas can affect an initiative taken within the public sector. There is a need for an earlier rehabilitation process, and as of today there is a need of a rehabilitation process to exist at all. The health care employees say there is no structured ways of rehabilitate the cancer patients today, and the patients say they feel left out after the treatment process when they have no appointments or meetings with the health care organization. With a structured way of handling the rehabilitation process, bringing the Försäkringskassan in earlier in order to establish a situation where the patient is able to focus on rehabilitation, and by starting it directly after a diagnosis is delivered, the overall system will gain advantages in terms of higher patient value throughout the entire life event. In the end of the process there could also most likely be a decrease in the long-term sick leave percentage, since more patients start processing their personal wonderings and problems much earlier, before the problems become overwhelming. The closer-working system is illustrated in the Figure 5.10 below.

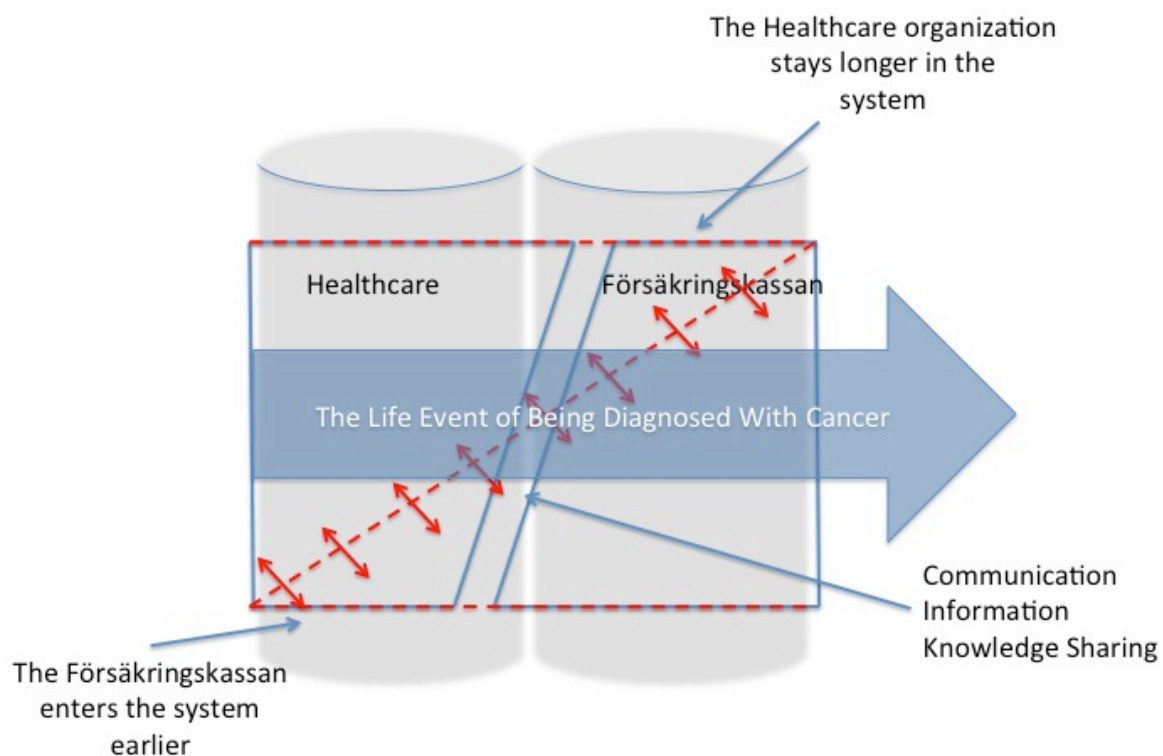


Figure 5.10 illustrates the Försäkringskassan entering the service system earlier, and the Healthcare organization stays longer

6. FINDINGS

This chapter will further summarize and help clarify the areas of problems, and improvement potentials found throughout the study.

INCREASE INDIVIDUAL PATIENT VALUE

The overall focus and goal expressed by the involved actors in the caring process tend to lean towards an increase in the individual patient value.. This could in fact result in an understanding and an awareness of all the different needs of an individual patient. Emilia expressed the need for a process aiming towards the same goal, where her all her fragmented needs were of importance.

PATIENT VALUE CREATING SERVICES

Seeing the process as a value creating service process is argued in the literature to be harmonizing with the perspective of considering the life event of getting a cancer diagnosis. The change from seeing the system as a production, and the use of production methods, to a more service oriented perspective of the system will help understanding the system gaps and the problems existing and occurring due to these gaps throughout the system process. The methods used could be service oriented and then focus on the patients, and how to create individual value, instead of primarily focusing on the different actions taken from the different actors involved.

By considering the system to consist of services, and by using the SERVQUAL model, the three different gaps could be identified. The first one was the gap between what the service providers think that the patients want, and what the patients really expects from the services. The second gap was the gap between what the services actually provide, and what the providers communicate that they will provide to the patients. The third gap considered was the gap between what the patients expect to receive as a service value, and what they actual do perceive. This will help the service providers see the importance of the gaps, and they can become aware of that the gaps exist, and therefore be able to consider possible solutions.

COMMONLY CREATED GOALS

On of the major challenges for the system as a whole, is the need for developing common goals for all actors involved to be part of. In the case of the public sector organizations there tend to be many improvement projects up running simultaneously by all different actors, but nothing is there to tie them together. Most of the times the involved actors do large investments in projects within their organization, but few of them open up their businesses in order to get other actors onboard. The majority of the initiatives might even counteract each other. The need for shared goals developed in consensus by all actors will link all small and large improvement initiatives together, and when focusing towards the same output they will boost each other into system effective results. It is not a matter of hiring some external actors to create the goals or visions, but instead force the involved actors together in order to create a common understanding of the future challenges. The organizations will need to schedule time for cooperation meetings and workshops where the focus on the day will be to brief the everyone of what is going on it the different organizations, and how the system as a whole can focus and gain advantages from the different initiatives. They can use tools and methods based on improvement projects such as the AIM tool, or the effective scoping in order to have structured and informative descriptions of how to go along with the gathered knowledge.

FLEXIBILITY WITHIN THE STANDARDIZED SYSTEMS

The system of the public sector organizations is standardized, and it has to continue to be that way since laws and regulations form the legal secure system of Sweden. However, there is a need for creating flexibility within the standardized system where individual values can be met and satisfied, without trespassing the Swedish law. This flexibility can be established through cooperation and open discussion among the involved actors, where the openness and the engagement are the most important factors. The silo organizations need to be overcome and start working cross-boundaries, in order to coordinate their initiatives. The organizations need to know what the others offer in the work of increasing the individual value, and start taking responsibility for the shared actions. Cross-sectional work and flexibility can be established through meetings, workshops, continuous improvement project initiatives, and knowledge sharing, in order to start focusing towards the same goal, the patients.

PROVIDE AND SHARE INFORMATION EARLY AND CONTINUOUSLY

This is the far most important finding of all, since it focuses both on the improvement of the system, and the improvement of using the patient as a valuable input to the system. As discussed earlier the patient has expectations based on previous experiences and information. The expectations do not always match the real world, and this can very fast cause frustration and great damage, especially when stress and pain affect the person. When a person gets diagnosed with cancer the individual treatment process is supposed to begin for this person, and here it is very important to start the process right. Since a person is constantly searching for information, in order to decrease the uncertainty of what is to come, valuable information needs to be available for the person to consume. There is a need for information regarding the process, the different steps, what to expect, what pain to feel, how to manage the pain, and information regarding how to deal with the outer life. This information will guide and help the patient to know what to expect, and when to expect it, in order to push the expectations closer to what the caring system offers.

This will prepare the person in the best possible way, in the easiest and most efficient possible way. The patient can read and search for the information when they want, when they have time, and especially when they are receptive. This will guide the patients into the standardized system of the public sector organizations, where they inside this system can be treated individually. The early information will decrease the variation of incoming patients, in order for the system to better focus on the flexibility within the standardized structure, rather than trying to push the patients outside the boundaries inside, and try to get them to understand what is possible. This will decrease the need of correction and disappointment among patients, and instead educating the patients in what their rights are. At the same time, it is important to include information regarding what is required by the patient in order to co-produce the individual value, and to do it as good as possible. It requires information regarding how to prepare for different treatments, when to send in papers, what papers to send in, how to manage the pain, how to deal with the outer life situation. It is of great importance neither the patient, nor the system sees the patient as the end user of the process, but rather as a valuable source of information and knowledge, and that they all start cooperating in order to increase the individual value as much possible for the patient.

REHABILITATION

To start the rehabilitation process early on, when the patient has being diagnosed with cancer could help increase the individual patient value, since their way back to a normal life will start form the beginning. The healthcare organization should not leave the process after the last treatment, but rather consider staying in the process longer in order to not lose the patient and all the effort put into the caring process.

7. RECOMMENDATIONS

In this chapter the recommendations and the solutions of the discussed problem areas will be presented. These are suggestions aiming towards an increase in the individual patient value. The Figure 7.1 below summarizes the areas of discussion from the previous chapter, and illustrates the imaginable future state of the service system process. The following recommendations are presented in a specific order, with respect to the importance of the recommendation.

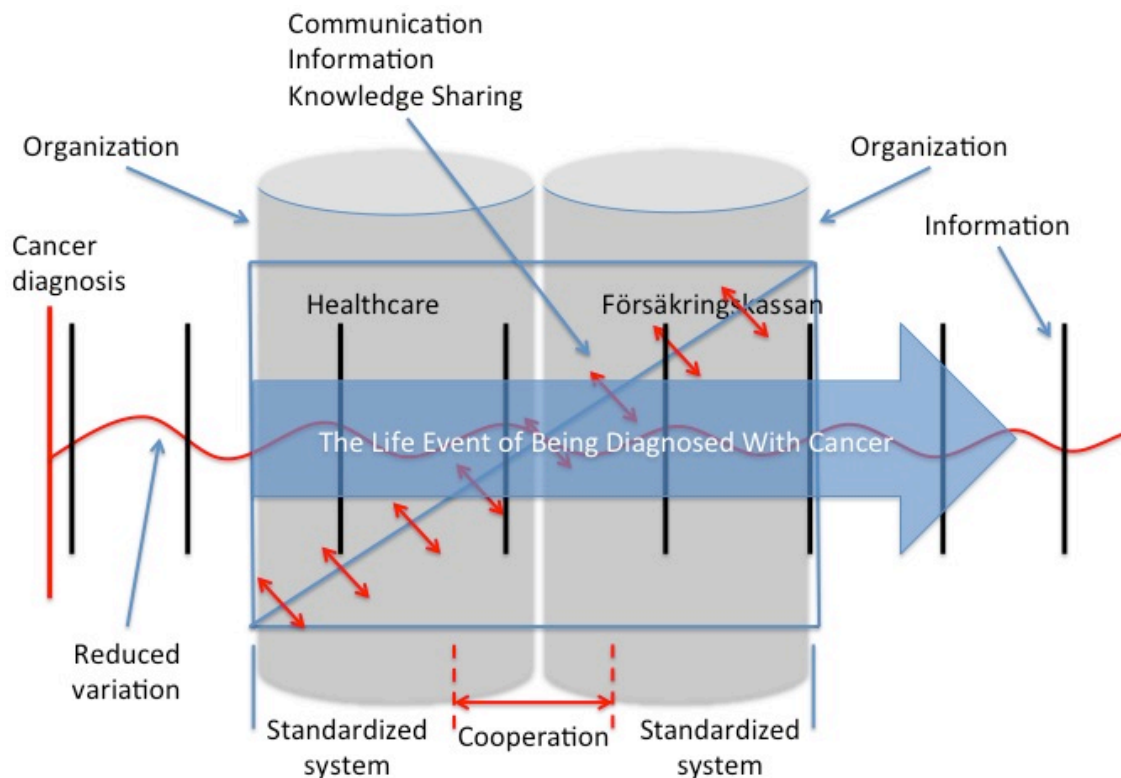


Figure 7.1 illustrates the future state of the individual value creating service process

INCREASE THE INDIVIDUAL PATIENT VALUE

There is a need from all actors to listen and involve the patient in the upcoming processes. The patient should be included in the creation of the value creating services as a co-producer. This could help understanding and interpreting the actual needs of the patient, and could result in increased individual value. Illustrated as the blue arrow in the Figure 7.1, the life event and individual value is represented by the arrow and has been put in front of all other actions. By offering the right services from the beginning, the patient can be cared for in a more individual and patient needs efficient way.

CONSIDER THE LIFE EVENT OF GETTING CANCER

To be aware and see the cancer diagnosis as a life event can help understanding the whole life perspective of the patient going through the caring process. It is important for all actors to zoom out and to get a solid picture of the many factors that affect an individual and not just see the particular action at the moment within the frames of an organization. More knowledge about what is needed by the patient outside the hospital can help providing the right caring processes and additional individual services needed in order to make the process as easy as possible. There could be room for flexibility and individual solutions suitable for a specific patient within the standardized system processes.

SEE THE SYSTEM AS VALUE CREATING SERVICES

Seeing the caring process as services harmonizes with the start of seeing a cancer diagnosis as a life event, in order to create individual value. To see it as services also helps understanding the existing system gaps between the expected and perceived customer value, and also the gap between what the patients' wants, and what the service providers think the patients want.

PROVIDE EARLY AND CONTINUOUS INFORMATION TO PATIENT

Information is needed to be handed out early on in the process, and continue to be handed out throughout the life event and the treatment process. Important information regarding the diagnosis, the waiting times what the process includes, and what that are required from the patient should be distributed to the patients in the early beginning when the diagnosis is given. This will give the patients control of the expected journey and information from one reliable source. The information could consist of written material, a platform at the Internet or a person to consult with. Important is to make the information accessible through different medias so that there always is one source of information that fits the individual.

One recommendation is also to provide all patients with an individual planning of the upcoming process as a folder. This could be seen as a schedule or mapping between the patient and involve actors of upcoming activities for example the following 3 weeks. This could give the patient a possibility to prepare mentally of the upcoming process.

COORDINATION OF THE SYSTEM

There is a need for someone to coordinate all of the different services in the process, in order to not lose the patient along the way. By tighter communication and cooperation the organizations could have some hubs where someone checks the patient travelling through the process, in order to make sure they are on the right track. For example could this be some kind of patient coordinator who has the whole picture of the patient's journey not just within the own organization but also at a higher system level. The coordinator could have contact with both Försäkringskassan and the health care in order to facilitate the processes for the patient and to be able to prevent complicated situations.

SHARED KNOWLEDGE

There is also a need for a common system for transfer information between health care and Försäkringskassan. A tool for the information transfer could be a checklist where the necessary information could be structured, visualized and be understood for both parties. This could then act as an information carrier for patients between health care and Försäkringskassan. Importantly is however that the checklist will be jointly developed so that both units early can give feedback of the checklist and make sure that it correspond to the information that you want to deliver.

There is also a lot of internal knowledge in the various units that could be taken care of in a better way than today. For example, by having officers who are specialized in cancer patients these would be able to share information with each other and build up a bank of knowledge regarding both diagnostic types, handling of personal feelings and important information for the patient. For the patient, this would also mean greater security and a great understanding from the officer. The officers could both be available on the phone as the system works today but also to come out to the cancer departments on the hospitals once a week to answer questions and get a closer contact with the patients. The overall goal is to link the services

tighter and to see the entire process as a whole, in order to establish a more secure and flexible system for the patients.

EARLIER AND STRUCTURED REHABILITATION

Försäkringskassan should enter the process in the early stages of the service process, because then the rehabilitation process will be given room and time to be started. Including the unit earlier will consider the system being able to handle the cooperation between the Försäkringskassan and the healthcare organization, and that the patient is being the focus of the planned future process. The rehabilitation would then continue throughout the entire caring process, in order to increase the possibilities of individualizing the process as much as possible. In the end of the treatment process it is of great importance that the Healthcare organization considers staying longer in the process, even though it might be other parts of the healthcare organization coming into play. This is in order to not leaving the patient alone after the treatments are over.

One recommendation is in the long run to establish a center for rehabilitation. Suggested is to provide the patient with a rehabilitation program within the center with possibility for adjustment for the specific individual. The center could act as a meeting point and source for information for patients during treatment, medical cured individuals, relatives and children. Within the center, life experiences, questions and ideas could be exchanged. It would also be possible to find support in other individuals with similar life events. Desirable is that both physical and psychical rehabilitation would be centered at one location. The center could also act as a venue for other stakeholders such as employers and where medical cured patients in need of a new employment could be paired with potential new job opportunities.

8. DISCUSSION

In this chapter a final discussion presented. The discussion aims both to question the areas addressed in the report, but also to show the areas in need of further investigation. The discussion will touch upon mainly four areas: areas where issues arose during the study, and areas that to some extent can be ambiguous and of further interest.

LEVEL OF INDIVIDUALIZATION

In this report, we have put considerable efforts to convey the needs surrounding personalization of processes in cancer care and at Försäkringskassan. Flexibility, patient involvement and adaptation to the individual have also been expressions that appeared frequently. Somewhere must also a question be asked, to what level can you push individualization? Are there disadvantages to having too much flexibility and term standardization as obsolete and something that should stay within the manufacturing industry? It is therefore important to reflect and highlight those aspects where the standardized system today actually aims to manage and treat patients and stakeholders involved in an effective, fair and safe manner.

The first thing that should be highlighted positively by the existing system is equivalence for all. The rules that exist around sick leave and health care programs protect individuals from being unfairly treated because of personal views of the officers or health care professional. People can feel confident that the system does not make exceptions in any direction but all go through the same assessments. It is also difficult for example, Försäkringskassan to know when to make exceptions and what those exceptions should be based on. To involve the patients in their own treatment is perhaps great at certain degree. As mentioned earlier in the report, the patient is the expert on his or her own situation and state of health of that specific

time. However, there may also be a limit, which doctors and nurses need to step in and pursue his or her professionalism, and judgments for be able do the best for the patient based on views from the health care without the patient's involvement.

The other thing that should be discussed is the compromise individualization might mean. Using standardized methods, many people could go through the processes at a certain time. With an individualization where every individual should form his or her own process in some extent, this could mean a longer time in the process. Waiting times that are already long in some places might be even longer. Therefore, it is important to discuss what the priorities are and possible consequences could be. Should we let many people still get a treatment and assessment quickly but with slightly less room for personal adaptation and flexibility or that the people who are going through the process shall be 100% satisfied with their own customized treatment but with possibly a longer lead-time. Optimal would obviously be both, and it is therefore important to always try to find the balance between standardization for efficiency and flexibility for personal treatment.

One possible solution, which could be just a hybrid between standardization and individualization, is segmentation. This is something Försäkringskassan started to work until recent times. In this way, the unit can sort the individuals in groups based on previously established criteria and apply more or less standardized methods on these individuals, depending on the needs of the group. Thereby they can add extra energy and resources on people in much need of help and support of the community but also let some people just pass through the system, which might also suit those individuals best. The segmentation is something the authors believe will have an increasingly great role in the care sector related processes in the future. This precisely because it is possible both to maintain efficiency but at the same time early identify of individuals who are in need of much support and help for a good life situation.

INDICATION OF NEEDS RATHER THAN PRESENTED SOLUTIONS

Something that the authors during the research felt as important is that external actors should not create solutions to perceived problems within the system today. In this early phase, it is more important to indicate the causes of the problems and the needs identified. By hire example consultants, who early present recommended solutions, underlying overall knowledge can be lost. The authors believe instead that it is important to continue the initiatives started with the collaboration of interaction days and cross-functional workshops, which make all players, get an opportunity to understand each other's activities and in the long-term be able to develop proposals for improvement. It is important that the both Försäkringskassan and The healthcare take action together and get involved in developing and implementing possible changes. This could also make the internal resistance against the new methods or ways of thinking are minimized. At the same time the solutions will probably be based on knowledge of the individuals who work closest to the processes.

THE ECONOMICAL ASPECT

An aspect that was raised during the thesis was whether or not the healthcare unit should be more economical responsible for their own actions, and especially when it comes to patient sick leave. Today, the doctors can give medical and subjective advice to patients in order for them to get sick leave from work, but the healthcare unit is not responsible for the economic consequences of these actions, but rather the Försäkringskassan is the economic responsible actor. This can be discussed whether or not this is the most efficient and suitable way to handle such matters of interest. It leaves the healthcare unit to act in a free environment

without any further consequences of their own actions. The Försäkringskassan is then responsible for determine whether or not the individual patient has the right to receive sick-leave allowance.

Another important economical aspect is how the implementations recommended in this thesis could affect the economic aspect. There will be resources and time needed in order to implement the changes, and in order for the implementations to be a natural part of the system. Some recommendations will require more resources, such as earlier rehabilitation and coordination of processes, but it does not have to be huge investments if they are planned ahead, and are very carefully considered. Most of the changes are change of mindset and values, in order for the system to come together and work as one unit, instead of separate actors. We believe that the resources needed could decrease after implementing the changes, in terms of increased cooperation and less unnecessary actions that do not add to the individual value. This is however an interesting field of study, in order to get the system working as a whole, focusing on the individual patient needs.

MEASUREMENTS OF IMPROVEMENTS

One important aspect when it comes to improving the processes, and the entire system in this case, is the possibilities of measuring results, and especially improvement results. In earlier work establishments we have seen that all different actors within the healthcare system somehow measure their own actions and initiatives, and this is of course a start, but if the entire system is to start working as a whole, new methods and goals need to be developed in order to measure the entire system improvement. This could be of great importance when evaluating the improvement results, but also when deciding if there should be an investment in a specific project. All stakeholders and actors within the system will see positive results from invested time and resources, and therefore it could be time to start developing measurement methods.

It could be very tricky to develop a measurement where different actors are to be evaluated based on their actions within one complete system, and where patients, secrecy, and subjective values are involved. It is not really computerized data coming out from the system that is the input in the improvement calculation, but rather patients' experienced value during their stay in the system. That is what we think should be measured based on the analysis in this report, but there is of course stakeholders that rather want to measure the actual output from the system, such as number of patients on sick-leave. These different views on how to measure and what to measure need to cooperate and be taken in consideration in order to involve all actors, in order to meet their different interests. However, they need to consider the fact that their actions might give better result if they start cooperating closely with other actors in order to create better result together.

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10. APPENDICES

10.1 APPENDIX I – Interviewees

In this appendix, the interview names we are able to state are included in the table below.

| Name | Actor | Date | Interview mode |
|------------------|---------------------------|-------------|-----------------------|
| Johan Quist | Specialist | 2014-10-09 | Telephone |
| Thomas Johansson | Försäkringskassan | 2014-10-16 | Telephone |
| Susanne Ottosson | Healthcare | 2014-10-27 | Personal |
| Gunnar Eckerdal | Healthcare | 2014-10-27 | Personal |
| Ulf Hallgårde | Specialist, Healthcare | 2014-11-06 | Email and telephone |
| Susanne Ottosson | Försäkringskassan | 2014-11-07 | Telephone |
| Louise Ahlgren | Försäkringskassan | 2014-11-18 | Telephone |

10.2 APPENDIX II – Interview Templates

Interview Template Patients – In the early beginning of the project

Information, kommunikation, tajming i processen, organisationsproblem/processen

Information

Vilken information fick du från vården vid ditt cancerbesked?

- Hur fick du informationen?
- Vad fick du leta upp själv?
- Var hittade du informationen?
- Hur lätt var det att hitta informationen?

Vilken information fick du från försäkringskassan i samband med ditt cancerbesked?

- Hur fick du informationen?
- Vad fick du leta upp själv?
- Var hittade du informationen?
- Hur lätt var det att hitta informationen?

Vilken information har du fått under din behandlingstid från vården?

- Hur fick du informationen?
- Vad fick du leta upp själv?
- Var hittade du informationen?
- Hur lätt var det att hitta informationen?

Vilken information har du fått under din behandlingstid från försäkringskassan?

- Hur fick du informationen?
- Vad fick du leta upp själv?
- Var hittade du informationen?
- Hur lätt var det att hitta informationen?

Vilken information har du fått efter avslutat behandlingstid från vården?

- Hur fick du informationen?
- Vad fick du leta upp själv?
- Var hittade du informationen?
- Hur lätt var det att hitta informationen?

Vilken information har du fått efter avslutat behandlingstid från försäkringskassan?

- Hur fick du informationen?
- Vad fick du leta upp själv?
- Var hittade du informationen?
- Hur lätt var det att hitta informationen?

Vilken information har du saknat?

Vilken information har varit av nytta och på vilket sätt?

Hur skulle du vilja att informationen du behövde presenterades?

På vilket sätt skulle en sådant information/informationssätt hjälpa dig?

Hur har samarbetet mellan vård och försäkringskassa fungerat?

- Har du fått samma information från båda aktörer?

Kommunikation

Hur kommunicerade vården cancerbeslutet till dig?

Vilken hjälp fick du av sjukvården med att starta din “pappersprocess”?

Kan du berätta med om hur starten av processen gick till?

Hur var din första kontakt med Försäkringskassan?

Hur fortlöpte kommunikationen med Försäkringskassan?

Hur kommunicerades informationen till dig?

Hade du tillgång till kontaktperson?

Processen

Är du nöjd med den information som du fått ta del av efter ditt cancer-besked?

- Från vården om vårdbeslut?

- Från Försäkringskassan gällande ekonomiskt och psykiskt stöd?

Hur ser du helst att informationsprocessen är uppbyggd?

Är det vid något specifikt tillfälle som du tänk att en viss typ av information vore lämplig att erhålla?

Timing i processen

Hur väl har information och kommunikation flutit mellan vård och försäkringskassa vid olika kritiska tillfällen?

Vid vilka tillfällen har det varit extra viktigt med ett gott samarbete mellan aktörerna?

Finns det några tillfällen då få saker har fungerat?

Vilka tillfällen under livshändelsen är mest kritiska att få tydlig information från vård och försäkringskassa?

Hur skulle den optimala situationen med hänsyn till kommunikation mellan försäkringskassa och vården se ut?

- Vid vilka tidpunkter?

Interview Template Patients – Later on in the process

Hur upplevde/upplever du din kontakt med försäkringskassan?

- Vid cancerbesked

- Under behandling

- Efter avslutad behandling

Vad har varit bra/ vad har varit mindre bra?

Fick du den information och hjälp du behövde från försäkringskassan?

- Vid cancerbesked

- Under behandling

- Efter avslutad behandling

Vad har varit bra/ vad har varit mindre bra?

Fick du den information och hjälp du behövde från vården?

- Vid cancerbesked

- Under behandling

- Efter avslutad behandling

Vad har varit bra/ vad har varit mindre bra?

Vilken information har du fått leta upp själv?

Hur har samarbetet mellan vård och försäkringskassa fungerat?

Interview Templates the Försäkringskassan Officers

Hur länge har du varit handläggare?

Vilka typer av kunder/brukare handlägger du?

Tycker du att någon specialgrupp behöver specialkunskaper för någon utav dessa grupper?

- I så fall varför?

Upplever du att cancerpatienter är en stor grupp?

Vad är ditt övergripande intryck av cancerpatienter?

Hur upplever du cancerpatienters situation?

Finns det vissa livssituationer som du snabbt kan identifiera och veta hur du ska hjälpa?

Är det några kriterier som en cancerpatient ofta behöver som du vet på förhand?

Har du något visst tillvägagångssätt/direktiv som du följer? Är samtalen och lösningarna flexibla?

Finns det utrymme för fritt spelrum inom vissa ramar?

- I så fall inom vilka ramar?

Är det en känslig kundgrupp för er?

Hur får ni stöd från Försäkringskassan om svåra beslut/situationer uppstår?

Är en ansökningsprocess komplex för en "vanlig" cancerpatient?

När blir det ett komplext fall för er?

Är det något du skulle vilja ändra på i processen?

- I så fall vad?

- På vilket sätt?

Interview Templates the Healthcare Employees

Hur upplever ni samverkan mellan vård och Försäkringskassa idag?

Vilka områden inom cancerprocessen upplever ni ur en patientsynpunkt som mest komplexa just nu?

Ur sjukvårdsperspektiv?

Hur tycker ni man skulle kunna individualisera processen samtidigt som man har kvar en standardisering för ex kostnadseffektivitet och kvalitet?

Vilka möjliga förbättringar ser ni skulle kunna göras för en ökad upplevd kvalitet hos patienterna?

Interview Templates Expert in the Field Johan Quist

"myndigheter producerar värde som medborgarna konsumerar" Tycker du att föreställningen är sann?

Är syftet att det skall vara så att myndigheten skall producera och leverera lösningar eller är det meningen att även kunden som utnyttjar servicen/processen skall bidra så värde skapas för kund?

Tillåts idag patienterna att samproducera tjänster tillsammans med myndigheterna?

När skapas egentligen värde?

Vad är värde ur ett service- och tjänsteperspektiv?

“Tjänster är lika, stordriftsfördelar enhetlig styrning”

Tror du att det är möjligt att ha en effektiv och standardiserad organisation samtidigt som att tjänster kan vara mer anpassade för individen som skall bruka den?

I så fall hur skulle detta kunna se ut?

“Standardisering och resurseffektivitet”--> hur kan best practice uppnås?

Vad tror du är viktigast för myndigheter idag: Att vara effektiva för att göra kostnadsbesparingar eller att det inte skall ske några undantag för individen och att lika för alla är det viktigaste?

Hur ställer du dig till frågan: Är det lika för alla om man har standardiserade lösningar?

Är lika för alla just lösningen att alla få ett och samma belopp eller möjligheterna till ett likvärdigt liv under exempelvis en sjukskrivning?

Interview Templates Expert in the Field Ulf Hallgårde

Ert projekt kring ökad samverkan

- Vem var initiativtagare och hur började projektet?
- Vad har din roll varit i projektet?
- Hur ställde sig försäkringskassan till det i början?
- Hur hittade ni argument för att få dem intresserade?
- Vilka var de största identifierade problemen i samverkan och hur identifierades de?
- Var det RCC som drev projektet eller alla tillsammans?
- Rehabkoordinatorer är som ni infört, hur och vem har anställt dessa?

Finns det några dokument vi kan få ta del av?

Vilka svårigheter har ni stött på ur samverkan vinkeln?

Vilket område har varit mest komplext?

Individanpassat omhändertagande

Hur jobbar ni med det?

Om ni inte jobbar med det, är det något du tror att man skulle kunna ha som framtida arbetssätt?

Vilka svårigheter och hinder finns?

Hur segmenterar man?

10.3 APPENDIX III – Effective Scoping

| SUPPLIER | INPUT | INPUT | PROCESS | OUTPUT | OUTPUT | CUSTOMER |
|----------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------|
| Q8b. Who supplies the input? Försäkringskassan Healthcare Patients Public sector | Q8a. What are the inputs to the system? Variation such as: - The patients, in terms of their individual life situation - Patients' expectations - Försäkringskassan officers - The doctors' notes | Q9. What does the system require of the inputs? Standardized solutions Low variation No differences | Q7a. Are there rules and regulations? Secrecy Ethics Silo organizations Different systems Independent goals Political decisions | Q1. What is the output? Standardized solutions - Not too satisfied patients - Increased long-term sick leave % - Unemployment - Treated patients | Q3. What is required of the output from the user? Communicate Understanding Care, guidance Individual solutions and value See the life event | Q2. Who uses the output? Patients |
| | | Future. - Could segmentation be of value? - Individual value | Q7b. What knowledge is needed? Mutual interests Process experts Focusing on the patients | Q6. What other measures cannot be lost in the process? Financing Time Sustainability Ethics | Q4. What measure should be understood and improved? Individual patient value | |
| | | | | | Q5. Can that measure be measured today? No Complexity Subjectivity Determine quality | |