



Assessing perspectives of values for eService development process of Renal Patients and their Next of Kin



Asteljoki, Sara

Laurea University of Applied Sciences

Otaniemi

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process of Renal Patients and their Next of Kin**

Sara Asteljoki

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Sara Asteljoki

Assessing perspectives of needs and values for e- Service development process of Renal Patients and their Next of Kin

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This study is part of an eService creation process targeted for renal patients and their next of kin. Laurea University of Applied Sciences Learning by Development (LbD)- model enables student participation to projects that are closely linked to working life. The original idea for the service creation came through an innovation process during a course of Innovative Business Management where students were given a task to brainstorm new target groups from the health care field that would benefit from designed eServices. Renal Patients and their Next of Kin became from the researchers nursing background.

The research was conducted through action research process and design research methods. Action research provided flexibility to assessment of online applications and solutions to be used as well as cyclical framework for conducting the research. Design research methods were used in data collection. This is a qualitative research and qualitative content analysis methods were used to analyze the data. The purpose of the research is to assess core values of the target group through the assessment of needs to support the eService creation process.

1) What kind of core values does the target group have based on needs?

2) What could be value adding eService for the target group?

This study as such does not provide information over business opportunities or health care service solutions. It was carried out to support and provide customer orientation for the eService creation process. Approach is abductive. Data collection was carried in three stages. 1) Short stories 2) individual interviews via Skype 3) group interview via Skype.

The whole process was carried through internet, which enabled low cost and easily accessible research possibilities. Communication between respondents and the researcher was carried through e-mails before individual interviews. Target group members were reached through co- operation with Kidney and Liver Association Musili. Due to internet based communication location of the target group members was irrelevant and participants were from different parts of Finland.

Five main value defining categories were defined from data analysis process: 1) Contributors to psychological values 2) contributors to physiological values 3) value of freedom 4) value of environment 5) value of social relationships. Conclusion to purpose of the research, the five categories could be used to support eService creation process.

Key words: eService, eHealth, Chronic Kidney Disease, Needs, Values

Otaniemi

Sairaanhoitaja (YAMK)

Terveyden edistämisen koulutusohjelma ja johtaminen perhetyössä ja perhehoitotyössä

Sara Asteljoki

Arvojen ja tarpeiden kartoitusta ePalvelun kehittämisen tukena munuaispotilailta ja heidän omaisiltaan

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Tutkimus on osa ePalvelun kehittämistä munuaispotilaille ja heidän omaisilleen. Laurea Ammattikorkeakoulun Learning by Development (LbD) - malli antaa mahdollisuuden opiskella työn ohella ja osallistua erilaisiin kehittämissuhteisiin. Idea ePalvelun kehittämisestä munuaispotilaille syntyi Innovative Business Management- kurssilla, jossa opiskelijat etsivät uusia kohderymiä terveydenhuollon piiristä. Työskentely sairaanhoitajana munuaispotilaiden kanssa antoi tutkimukselle idean kohderyhmästä sekä toi mukanaan tutkimuksessa tarvittavaa työkokemusta.

Tutkimus toteutettiin toimitatutkimuksena käyttämällä design -tutkimuksen menetelmiä . Toimintatutkimus mahdollisti joustavuuden tutkimusprosessissa. Design - tutkimuksen menetelmiä käytettiin aineiston keruussa. Tutkitulle aineistolle tehtiin laadullisen tutkimuksen sisällönanalyysi.

Tutkimuksessa tarkastellaan kohderyhmän arvopohjaa, jonka perusteella voidaan luoda ePalvelu. Tutkimus vastaa kysymyksiin: 1) Minkälainen arvopohja kohderyhmällä on ? 2) Mikä voisi olla lisäarvoa tuottava palvelu kohderyhmälle?

Aineiston keruu toteutettiin kolmessa osassa. Ensimmäinen osa oli lyhyt, vapaamuotoinen tarina, toisessa haastateltiin tutkimukseen osallistuneita, jokaista erikseen ja viimeisenä oli ryhmähaastattelu. Haastattelut tapahtuivat Skypen välityksellä.

Tutkimus toteutettiin internetissä. Internetin käyttö oli sekä kustannuksiltaan että että kattavuudeltaan tehokas tapa saada tietoa. Tutkimukseen oli mahdollista osallistua koko Suomesta, asuinpaikasta riippumatta.

Tutkimuksen tuloksiksi sisällön analyysin kautta saatiin viisi kohderyhmän arvoihin vaikuttavaa tekijää tai itse arvoja: 1) tekijät, jotka vaikuttavat psykologisiin arvoihin 2) tekijät, jotka vaikuttavat fyysisiin arvoihin 3) vapauden arvo 4) ympäristön arvo 5) sosiaalisten suhteiden arvo. Tutkimuksen tuloksia voidaan hyvin käyttää ePalveluiden innovatiiviseen kehittämiseen. Tutkimuksen suorittaminen internetin välityksellä osoittaa kuinka tehokkaasti on mahdollista kartoittaa eri potilasryhmien ePalvelun tarvetta

Avainsanat: ePalvelu, eTerveys, Krooninen munuaissairaus, arvot, tarpeet.

Table of Contents

1	Introduction	2
2	Purpose & Aims	4
3	Literature Review	4
3.1	Internet, information and health provision.....	4
3.1.1	eHealth and Telemedicine	5
3.1.2	Quality of online health services.....	6
3.1.3	Skype.....	7
3.2	Patients with Renal Diseases	8
3.2.1	Stages of Kidney Disease	9
3.2.2	Quality of life (QOL); perspective towards chronic illness	11
3.3	Perspective towards needs and values	12
3.4	Maslow's hierarchy of needs	14
4	Methodological background	17
4.1	Action research	17
4.2	Qualitative Design Research.....	19
4.3	Abductive approach.....	20
4.4	Data Collection and methods for analysis	20
4.4.1	Pre- online phase	21
4.4.2	Online phase.....	22
4.4.3	Feedback of the interviews	23
5	Data analysis	23
5.1	Data analysis of short stories	24
5.2	Data analysis of individual Skype interviews	24
5.3	Data Analysis of group discussion	25
5.4	Reflexive journal	26
6	Results	29
6.1	Responses with descriptive words to five major categories	29
6.2	Five core values or contributors as final results.....	30
6.3	Contributors to psychological values	30
6.3.1	Self image.....	31
6.3.2	Emotions	31
6.4	Contributors to physical values.....	31
6.4.1	Value of illness and Health.....	32
6.4.2	Value of Food.....	32
6.4.3	Value of Rest	32
6.4.4	Value of Senses.....	33
6.5	Value of Freedom	33
6.5.1	Value of Time	33

6.5.2	Value of Responsibilities and Duties	34
6.5.3	Value of activities during treatments	34
6.5.4	Value of freedom and independence.....	34
6.6	Value of the Environment	35
6.6.1	Example of traffic	35
6.7	Value of Social relationships	35
6.7.1	Family and Next of Kin	36
6.8	Concluding results.....	36
7	Discussion.....	36
7.1	Ethical issues.....	36
7.2	Trustworthiness.....	37
7.3	Discussion of findings	39
7.4	Challenges	42
	REFERENCES.....	43
	FIGURES.....	45
	APPENDIX 1 Osana Iloisten asioiden edistämistä?	46
	APPENDIX 2 Arvopohjakartoitus munuaispotilaille ja heidän omaisilleen suunnatulle virtuaalipalvelulle	47
	APPENDIX 3 Hei Kaikille :)	48
	APPENDIX 4 Hyvä tutkimukseen osallistuja:.....	49
	APPENDIX 5 Data Anaysis grouping by data source.....	51
	APPENDIX 6 Original quotations	59

1 Introduction

This research is part of an eService creation process targeted for renal patients and their next of kin. Laurea University of Applied Sciences and Learning by Development (LbD)- model enables student participation to projects that are closely linked to working life. Original idea for the eService creation process came through an ideation process on a lecture of Innovative Business Management, students were given a task to brainstorm new target groups within health care field that could benefit from utilizing new technological solutions. The target group for this research was renal patients and their next of kin. Due to the researchers nursing background and some working experience with the target group, ideation and innovation process took place. Thoughts were shared among professionals working with renal patients and how this research could support the actual service creation process. It was also clarified through continuous assessments of principle lecturers and the researcher.

Initiation of the idea was in the beginning of 2010. Background information of eHealth, solutions of telemedicine and available eServices were conducted throughout. This research was implemented in a relatively short period of time between September and November 2010, completely through internet. Voluntary participants were found through co- operation with Kidney and Liver Foundation MUSILI, and their local representatives. The location of the participants was irrelevant due to internet's endless possibilities. A demand for participation was the ability to use internet. Initially six participants volunteered, however, two dropped out of the process without notification, one was unable to attend and three participants were in an active role. Also one ad hoc next of kin was interviewed. Communication between researcher and participants was carried through e-mails and Skype voice calls.

The research was conducted through action research process and design research methods. Action research enabled flexibility to assessment of online solutions as well as cyclical framework for conducting the research. Design research methods enabled participant's use of imagination and were used in data collection and data collection design process. The research is a qualitative study that had abductive approach. The data was analyzed through qualitative content analysis methods and was collected from three different sets 1) short stories 2) individual Skype interviews 3) group Skype interview.

The purpose of the research was to assess core values of the target group and it aims to support eService creation process. The research questions were:

- 1) What kind of core values does the target group have?
- 2) What could be value adding eService for the target group?

Research results from all data sources were similar. And five core contributors to values or values as such were identified. Those were

- 1) Contributors to psychological values
- 2) Contributors to physical values
- 3) Value of Freedom
- 4) Value of environment
- 5) Value of social relationship

All five were found through qualitative content analysis and reflection towards chronic illness and perception towards life e.g. theoretical background for the research. The findings can be seen supportive and used as supportive themes for eService creation process. How beneficial the findings are; could be researched as such. However, the overall process was surprising and interesting, easy to conduct from technological perspective, and provided insight towards understanding of the target group.

2 Purpose & Aims

The purpose of the research is to assess core values of the target group and it aims to support eService creation process.

- 1) What kind of core values does the target group have?
- 2) What could be value adding eService for the target group?

3 Literature Review

In the late eighties and the beginning of the nineties the creation and implementation of the World Wide Web accelerated the ultimate global network. By the time of rapidly growing use of www, Internet had existed already for the past twenty years. Initially the World Wide Web was created to be “a pool of human knowledge”; fast transformation of information was enabled. Already in 1981 in the EEC Conference on the information Society held in Dublin, Masuda accurately predicted and defined the revolution of information technology. He stated information to become a “utility good” and that a transformation of societal systems would occur due to the phenomenon (1981, 55-56). It can be said, internet has become an important part of daily practice and rhythm of society has been affected through service provision. It has changed the world of services enabling ongoing growth of new technology and innovations. Social aspects of the Internet are widely recognized.

Online communication is based on user participation and over the past years researchers have focused on studying online behavior. Internet itself provides endless possibilities for service structures e.g. as we have seen change in the banking systems. Government, universities, hospitals, businesses and media need internet based solutions to keep organizations up and running. Discussion groups have been found to be more value enhancing than professional services (Gummerus 2010, 425).

3.1 Internet, information and health provision

In health care field, use of technology has seen through the medical history and industrialization era. Various technical aids and equipments are used on daily clinical settings to improve time consumption; simply aiming to make clinical practice easier and more efficient for health care providers and receivers. The need for well being services is ever growing and internet based services are invading into the field. EHealth applications and health related information is accessible to everyone. Education has reached new level over the internet and critical mass usage (Han, J.Y., Hawkins, R., Shaw, S., McTavish, F., Gustafson, 2009, 113). Health related information is available in its entire context. Han et al. note in their research

among cancer patients that Internet scores second in obtaining cancer related information after their physician (Han et al. 2009, 113). Undeniably, to their conclusion, internet has power and serves as a utility good. Research based on online behavior shows repeatedly results of how and where people receive health related information. Armstrong and Powell explored patients perspectives concerning health advice posted on online discussion boards. They identified three major categories: 1) the importance and value of peer support 2) awareness of the need to evaluate the information 3) the value placed on similar experiences (2009, 313). They also note cost- effectiveness and the need for long- term patients want to interact with peers (2009, 313). Computers and internet serve as a link so that interpersonal functions can occur between people (Han et al. 2009, 115). Consumer aspect is important as well, which this research aims to support. Winter (2008, 49) studied consumer patient aspect of eHealth and concluded that

eHealth is driven by consumer patients readily embracing cyber medicine to access health information.

3.1.1 eHealth and Telemedicine

At this stage it is necessary to make separation of terminology used with health related online services. Commonly, the technology behind defines the term used in literature and common language. Terminology of health related online services was properly developed in the beginning of the 21st century alongside new innovations. Initially the health care services were provided through telecommunication systems and referred as telehealth. Barnard & Locsin (2007, xv) defined:

Telehealth is the delivery of health- related service, enabled by the innovative use of technology, such as videoconferencing, without the need for travel.

This definition applies as the ground for many services provided by health care professionals in different health care fields. However, another term, more frequently used is eHealth. The term covers all online health services and therefore can be considered as rather vague. Maheu (2000:2) specifies the term:

eHealth refers to all forms of electronic healthcare delivered over the internet, ranging from informal, educational and commercial “products” to direct services offered by professionals, non- professionals, businesses or consumers themselves. eHealth includes a wide variety of the clinical activities that have traditionally characterized telehealth, but delivered through the internet. Simply stated, eHealth is making health- care more efficient, while allowing patients and professionals to do the previously impossible.

Maheu's thought contributes to previously mentioned reliability and trustworthiness aspect of health services provided online. Technology clearly enables real time service provision for various fields, but setting standards for professional services is challenging. To quote Winter, (2009, 49) who separated online health behavior from the consumer- patient perspective:

Various web-based pathways facilitate health related information exchange such as:

- *general- purpose search engines*
- *Health purpose search engines, which screen the Web sites for accredited quality markers*
- *Web portals or gateways channeling consumers to selected (quality assessed) health sites*
- *Virtual communities exchanging information through peer- to peer communication*
- *Advanced search services searching (for a fee) current databases for current and comprehensive medical information*

An ongoing development and assessment of how virtual media can be used to benefit people brings also challenges to health service providers. Underlying issue is to set standards for quality health care services. Due to the characteristics of Internet's social participation and action; "everything for everyone", it is vital to remember how reliability is expressed and what kind of information is provided by various sources.

3.1.2 Quality of online health services

Quality of professional health- online services can be difficult to identify. However, the growing need for new perspectives in the online development shall eventually set clear standards for eServices. Service providers need not only to think professionally but to recognize the consumer aspect of online services. Ethical and legal issues shall be considered and strategies created for risk management.

Media has discussed the growth of health care field in recent years. Need of private companies and services are widely recognized as the chronic demand for health services is growing. Health is everyone's concern and therefore the need is present at all times. More targeted markets are evolving through the possibilities of internet.

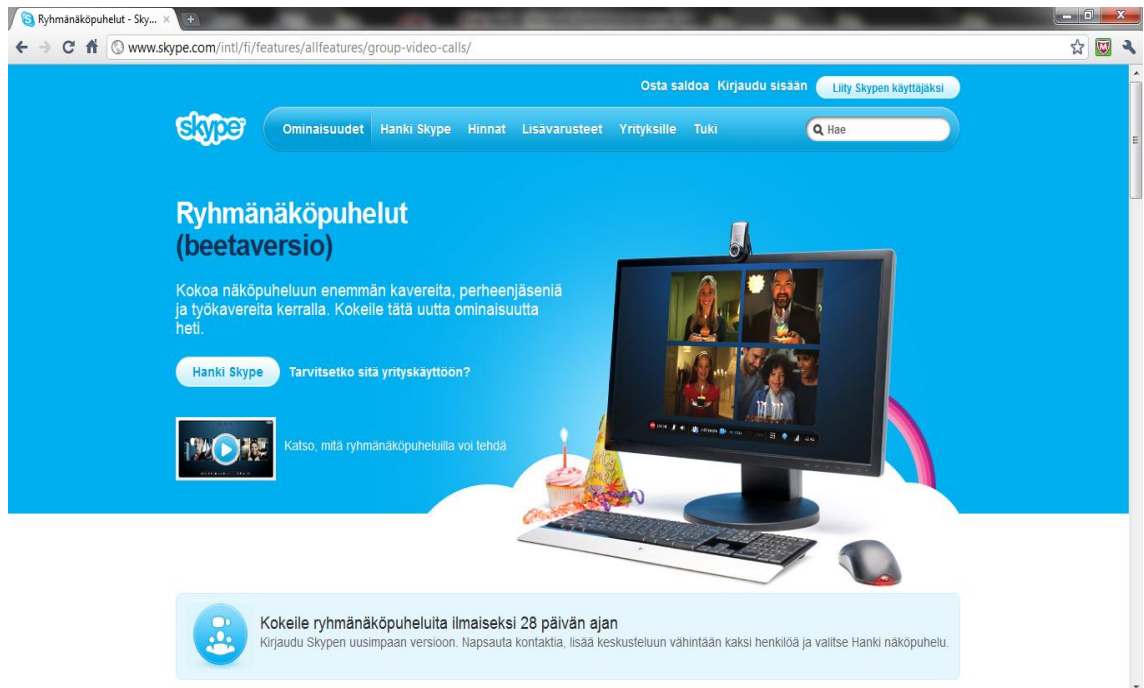
Importance of the development lies on the growing population of elderly people. How the ever growing group is treated and supported. Laurea University of Applied Sciences has supported and created CaringTV concept as one example of an innovative approach to provide health services through teleconferencing technologies. Rajj & Lehto (2008, 482) describe:

Caring TV is a two channel interactive TV system through which guidance and support are given in the form of various participative programs to improve and promote the

capacities of elderly people living at home.” The Caring TV® concept has been researched and developed through action research process and today is a functioning forum for the elderly for social interaction and participation in services. Through research it has been found to reduce loneliness and to increase the quality of life.

3.1.3 Skype

Skype is an internet based phone call service that has over 560 million in the end of 2009 (Gigaom 2.12.2010). It enables free phone calls to Skype users from around the world with an option of video footage. It has a feature for conference calls and social group calls (www.skype.com 2.12.2010). In this research Skype was chosen for its free of charge feature and usability by first time users. Clear instructions are provided on Skype web site for download. To use Skype a microphone is needed for communication which often is already installed in computers. Also use of head set is possible to enable privacy and in a case of absence of microphone in the computer. Skype uses secured lines; however the quality of voice calls may have technical difficulties related to absence of voice, overhearing other conversations and sudden cut downs of calls. (www.skype.com 2.12.2010)



Picture 1: Snap shot of Skype www site; group calls (www.skype.com 2.12.2010)

3.2 Patients with Renal Diseases

It is in the interest of whole society to find new service solutions in the ever growing health care demand. This research focuses on chronically ill kidney patients and their next of kin. However, the emphasis of this research relies on finding values that an eService development could benefit from. Therefore the target groups underlying medical conditions are not dealt in detail in the study. This chapter presents background information of the target groups underlying disease, in a rather broad way and based on literature, only to provide understanding why the group was chosen for research purposes.

Chronic illness is permanent despite of new technological solutions and medical development. With undeniable benefits to medicine, innovations also bring secondary problems, but chronic illnesses are not age related and are always discomforting for the whole society and individuals (Strauss and Glacer (1975, 3).

Chronic Kidney disease is a disease where one or both kidneys are damaged and are not functioning properly in order to maintain balance within the body. Even though the underlying cause would have been treated, it is common that the physical condition continues to decrease. The aim of treatment for kidney patients is to slow down the progress of the disease (Holmia, S., Murtonen, I., Myllymäki, H., Valtonen, K.,2001, 483- 485). Treatments for the CKD are medications, dialysis and transplantations. Dialysis treatments: Hemodialysis (through blood) or continuous ambulatory peritoneal dialysis (CAPD) (treatment through the peritoneal membrane) (Holmia et al. 2001, 486-487). The goal of these treatments is to secrete metabolic waste from the body to help the body maintain its balance. Kidney transplantation is the primary goal for kidney patients. Results for transplantations in Finland are highly successful, however, sometimes it is not the cure for the disease; the main threat after transplantations is the rejection of it (Holmia et al.2001, 491).

Chronically ill patients need continuous follow ups and guidance to maintain the optimal metabolic balance. This, in practice, means that they often have to visit hospital polyclinics. The treatments are based on medical assessments and dialysis treatments are usually indicated when the patients kidney functioning is only 5-10% (Holmia et al 2001, 487). Depending on the type of dialysis treatment and individual physical condition, the duration of treatments is carefully assessed. However, to provide an example of time consumption in dialysis treatments: hemodialysis treatments can vary from 2h/ day or 5h/ every other day x 3/ week. If, for example, hemodialysis is carried through night time, the duration of the dialysis is usually longer. To note, that the duration of treatment is always assessed on individual nursing care plans and has many variables that affect it. It is vital for CKD patients to maintain their physical condition on an optimal level, in order to receive kidney transplantation. Guidance, edu-

cation, support, receiving information and continuous maintenance of doctor patient relationship is vital. To quote a senior Nephrologist:

It is said that the relationship of a physician (nephrologist) and the patient lasts longer than an average marriage in Finland.

He was referring to the lifelong chronic illness and the profound medical relationship that health care professionals and patients encounter over a long time period for treating the patients.

3.2.1 Stages of Kidney Disease

Rough estimate is that there are 3000 patients receiving dialysis treatments in Finland (Suomen Munuaistautirekisteri 2008, 5), and the number is estimated to grow with 500 patients/year. Number of kidney transplantations is approximately 200/ year. (Hyssälä KK 432/2002).

The process of kidney disease is presented in stages in this thesis in Figure 1. In all stages special medical assessments are carried out by a multiprofessional team with the patient. The presentation of illness does bring relief as well as difficulties and permanent changes to the individual's life style. Health related quality of life is affected, in both positive and negative ways, as well as whole image of oneself. However, it has to be noted that the indications and symptoms for dialysis treatments are medically well defined and treated. The long lasting, demanding treatments can be exhausting. Medically, this patient group is under continuous "surveillance" and probably view health care from different perspective, then those who visit health services on "when needed" basis.

The disease is accompanied with restrictions to diet and fluid intake. Various other daily activities are affected, such as lifting or carrying heavy weights. Time organization changes and is planned according to the treatments. Nutritional support is important for patients to maintain electrolyte balance on an optimal level. Nursing care is focused on guidance and support in this perspective (Holmia et al. 2001, 488). To avoid the complications of reduced renal functioning, patients are dealing with a life threatening illness to cope in everyday life (Smeltzer & Bare 1999, 1155). Due to the threat, secondary problems and emotional stress are usual, especially at the stage of diagnosis. Anxiety, depression, self-esteem disturbances, fatigue, anemia, sexual dysfunction and change in self image are common. Social support is vital, from the health care staff and even more from the next of kin (Smeltzer & Bare 1999, 1155) However, changes in social relationships are not uncommon, old connections may find it difficult to interact and to cope with the situation and become distant. (Holmia et al. 2001, 488).

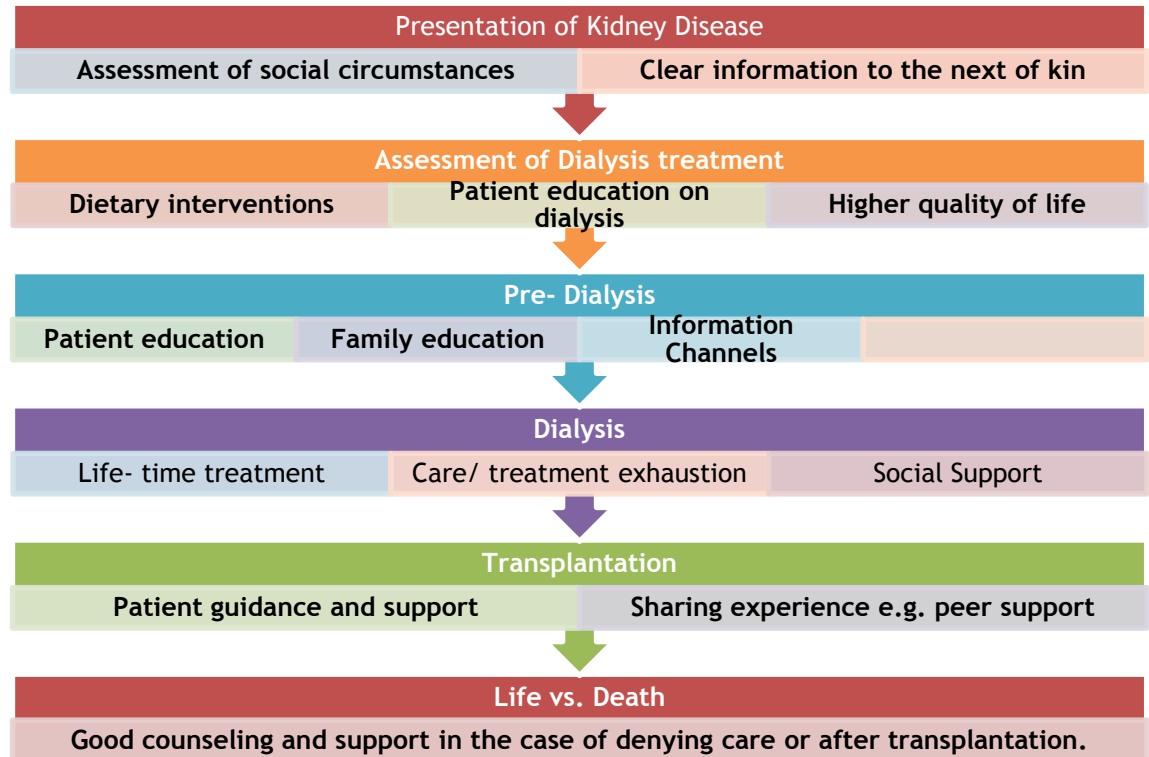


Figure 1: Summary of the stages of kidney disease and treatment process. The lower boxes present related themes in all stages from social and behavioral aspects, the table is based on Oxford Handbook of Dialysis (2004, 18-106)

The background knowledge for this research of the target group came from the researchers' background in nursing. One year working period, three years prior to the research, provided initial knowledge for the ideation of the whole service creation process. Knowledge and understanding of special features and delicate matters that kidney patients and their next of kin undergo, contributed to the decision making for this research. Tacit knowledge gathered through nursing processes, understanding medical features and procedures as well as the effects on social relationships through the onset of the disease, came through that experience. The next chapter provides definitions for quality of life, which is important for creating an understanding perspective towards quality of life and chronic illness.

3.2.2 Quality of life (QOL); perspective towards chronic illness

As a concept QOL is multidimensional and has variety of meanings and interpreters. Hundreds of definitions of quality of life have been made by researchers. Yet, they all seem to aim to the meaning of improvement towards person's interpretation and experience of daily life. There are various factors that constitute to the perception of quality of life; health, physical functioning, social factors, life- style, financial status and all issues related to the individual perception of life. To view the concept of health and the effect of chronic illness is important.

The constitution of World Health Organization (WHO) defined health in 1946:

Health is a state of complete physical, mental and social well-being and not merely the absence of a disease or infirmity. A definition with high demands that rarely are met in people's everyday lives, it could be argued that this definition could be a goal to aim towards; yet impossible to many to achieve.

As Strauss & Glacer stated (1975, 3), chronic illness brings permanent changes to individuals and to everybody's lives and therefore WHO's concept of health will most likely be viewed from different perspective.

Ottawa Charter for Health Promotion First International Conference on Health Promotion in 1986 defined health promotion and health as:

...the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well being, and individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the object of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector but goes beyond healthy life styles to well-being...

This definition is broader and provides comprehensive understanding over the fact that health as such can be seen from an individual perspective, even with an underlying disease, that is to state that health as a concept is relative and has variety. Especially, when an individual has a chronic disease, the concept of health may differ of a "healthy" person. To present the other perspective from literature, Valderranano et al (2001, 443-464) define the QOL for renal patients as follows:

Health related QOL refers to the measure of a patients functioning, well-being, and general health perception in each of three domains: physical, psychological, and social. Along with survival and other types of clinical outcomes, patient QOL is an important indicator of the effectiveness of the medical care they receive. QOL of patients with end-stage renal disease is influenced by the disease itself by the type of replacement therapy. Numerous studies have identified the effect of such factors as anemia, age, comorbidity, and depression on QOL.

QOL as a concept is wide and researched topic as such. In this research it is only expressed in order to provide comprehension for the reader. Service providers, online or health organizations aims towards higher quality of life for individuals. In this context the approach; supporting eService creation process is through the value perspective. Understanding the changes in perception of life through the onset of a chronic illness is important for creating solid customer understanding.

3.3 Perspective towards needs and values

Psychology, sociology and economics study human values and perceptions, providing different angles and also meaning to “value”. In this research focus is on target groups’ daily needs and values; that might contribute to eService development process by providing insight to customer understanding. Customer understanding here means the understanding of what areas could be beneficial for the user. Although, this research is not focusing on exploring business perspective of customer orientation, rather focus is on holistic approach that strives from ethical health ideology within the service creation process. Due to special characteristics of the target group; needs and values are to be assessed in order to create comprehensive knowledge of their perception towards daily life. Several methods and ways of reflecting needs and values exist in literature. For this research Maslow’s hierarchy of needs was chosen to guide the analysis process. Some may argue that values are not based on needs, but the distinction between a “healthy person” and an individual with a chronic illness is done to specify; why it is necessary approach values from the perspective of needs. To quote Miltz:

Some while ago, I had a discussion with a medical colleague who devoted many years of her life to psychotherapeutic practice with the chronically ill. During the discussion, she pointed out that the concept of health, as it is generally accepted, has little relevance for her patients. For them, health is not a matter of returning to the situation prior to the illness. Instead, they focus on the possibility of coping with the illness, of personal development and of a different lifestyle. A re-evaluation of personal knowledge and experience, confidence in the future and the conviction that life can be meaningful despite the illness are now central factors in their recovery and in the healing process. These factors help them to find new hope and motivation,

to make new plans, and finally, to seek new objectives, strategies and values. A different understanding of oneself and others and changes in personal attitudes and behavior provide the chronically ill person with various possibilities for becoming a „healthy ill person“. (Miltz, WHO 44: 32, 2)

It can be argued, that a person, who doesn't have a chronic illness, doesn't have a perspective of thought of how needs, or fulfillment of needs can be a value as such. But for an ill person, fulfillment of needs, through treatments for example, is fulfilling basic human value. To provide a harsh example to prove a point: a person has a need to void, but is unable to go to toilet without assistance due to a disability. There is no one to help, and an accident of wetting the bed happens. Shame, uselessness and bother for others may diminish the basic human value; being respected and helped to maintain individual integrity. Maintaining integrity is essential, a basic need and yet a value with an enormous importance.

This thesis is not based on philosophical perspectives of right and wrong, the theories of morality, rather on the perspective of chronically ill and their daily life. It is unnecessary to reflect various philosophies in relation of service creation process. However a slight insight shortly is appropriate. Immanuel Kant and Thomas Hobbes defined morality and human values from two perspectives that are seen as ground theories for exploration of values. Purhonen simplifies that Kantian perspective of values is based on individual goals that are not violated or treated as a means for use. View of Hobbes, however, is value of an individual to other individuals, this is gained via positive interaction and benefits for others. (Purhonen 1/2010). Integrity is closely linked to the questions of right and wrong. However, maintaining human integrity and providing ability to maintain physiological integrity from health providers' aspect include aspects of safe environment, basic physiological needs, psychological needs, social needs and right to adequate health support.

Values from societal perspective; religions play significant role. In Christianity: faith, hope and love are the basic values for life. In the history of ethics beauty, truth and kindness are named to be the three pillars. Finns perceive home, religion and fatherland as foundations for the society (Aaltonen et al. 2003, 128). The three latter guide legislation and political decisions; these reflect upon individual values that Maslow's theory presents, and implicitly contribute to the perception towards life. Aaltonen et al. view "life as a whole" from the perspective of values and they include 1) professional ability 2) physical ability 3) psychological ability 4) spiritual ability 5) social ability 5) financial ability to contribute to individual goals and aspirations. Values in everyday life can be researched through these different factors via reflection (Aaltonen et al. 2003, 59).

To conclude, actions are guided by needs and values in individuals' daily life. Aspirations based on history, experience and demands of various factors. Assessment of values through

reflection of needs is indicated to find out beneficial information for the use of the target group.

3.4 Maslow's hierarchy of needs

Values in general are viewed as individual choices in daily life (Aaltonen et al.2003, 13). To what are choices based upon in daily life? Famous psychologist, Abraham Maslow presented the theory of the "hierarchy of needs" and motivation theory for the purpose of exploring individual behavior.

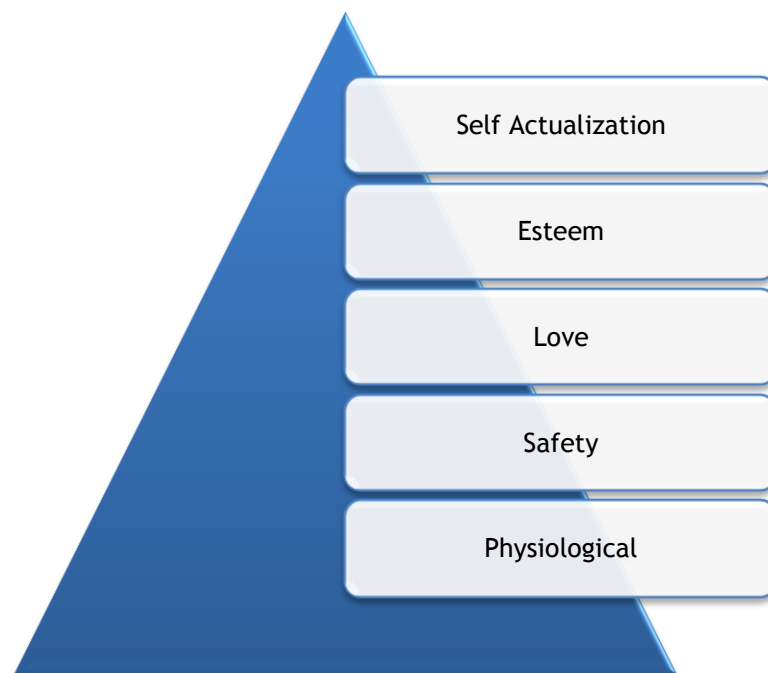


Figure 2: Maslow's hierarchy of needs

The first stage is self actualization that refers to the actions, potential and ability that an individual desires to become. It includes aspects of:

Morality, creativity, spontaneity, problem solving, lack of prejudice, acceptance of facts

The second stage, esteem, is the stage what is necessary for all people, to become accepted and valued as an individual:

Self esteem, confidence, achievement, respect of others, respect by others

The third stage is love that refers to the need of being loved, accepted and emotionally important within social groups and relationships:

Friendship, family, sexual intimacy

The fourth stage is safety, which includes necessities for survival, such as physiological needs, and environmental needs:

Security of body, of employment, of recourses, of morality, of the family, of the health of property

The fifth stage of the hierarchy is the stage that gives grounds for an individual to pursuit towards the higher stages of the pyramid. That is the basic human physiological demands:

Breathing, food, water, sex sleep, homeostasis, excretion (Simons, Irwin a, Drinnien 1987: 26.11.2010)

There have been arguments towards the hierarchical approach, however in this thesis the stages that are clearly defined guide the reader to understand also the stages of the kidney disease. Structures of the theories provide clearer underlining of how needs is affected and how values and basic daily life is changed through the onset of the illness.

Maslow explains as follows:

There are at least five sets of goals, which we may call basic needs. These are briefly physiological, safety, love, 'esteem, and self-actualization. In addition, we are motivated by the desire to achieve or maintain the various conditions upon which these basic satisfactions rest and by certain more intellectual desires.

These basic goals are related to each other, being arranged in a hierarchy of prepotency. This means that the most prepotent goal will monopolize consciousness and will tend of itself to organize the recruitment of the various capacities of the organism. The less prepotent needs are minimized, even forgotten or denied. But when a need is fairly well satisfied, the next prepotent ('higher') need emerges, in turn to dominate the conscious life and to serve as the center of organization of behavior, since gratified needs are not active motivators. (Maslow 1943, 370-396)

To simplify, if one of the needs presented in any of the stages is not met; an individual faces a need and acts to fulfill the need. All stages are connected and these have various dimensions, some are strongly affected and some are relatively less. However, the reason to present Maslow's theory is to present the connection to the values that guide actions in daily life. When reflecting upon CKD patients to Maslow's theory all five stages are affected and an individual is facing various changes. To refer to the previous chapter of CKD patients and how Maslow's hierarchy can be reflected in a simple manner: firstly: in the level of self actualization, spontaneity is affected through the onset of dialysis treatments; treatments are scheduled and become a routine. Secondly: level of self esteem can be impaired because of

changes in physical appearance; medicines affect through swelling or dry skin and possibly insertion of dialysis catheters that may affect to self image. Thirdly, change in social relationships may occur, the need for love and belonging increases. Fourthly, the security of body is threatened by a life threatening illness, employment possibilities may weaken or sick leaves may be extensively long which affects to financial situation. And the last, yet the most important physiological needs which include sex life, mental and physical well being, sleep and nutrition are affected.

4 Methodological background

The research was conducted through action research process and design research methods. Action research provided flexibility to assessment of online applications and solutions to be used as well as cyclical framework for conducting the research. Design research methods were used in data collection. This is a qualitative research and qualitative content analysis methods were used to analyze the data. Time frame for the research was from September 2010 to November 2010. Final results were presented in December 2010.

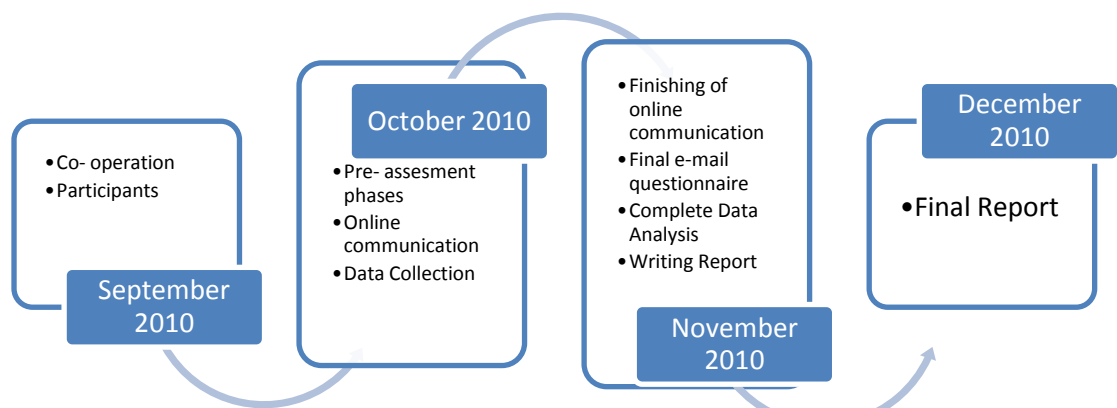


Figure 3: The time frame of the research process

4.1 Action research

Action research method was chosen because it enables voluntary participants' critical evaluation and feedback as well as the researcher's reflective approach towards the research process. There is variety of approaches within action research. The most suitable for this research process was the external action research:

...the researcher may be independent of the professional context, but work within it and alongside professional practitioners (for example, business leaders, managers, trainers or health professionals) to achieve change. Hence, action research is a process of collaboration for bringing about change. The exact nature of this collaboration, however, may be problematic (Gray 2009, 171).

The researcher was part of the research process by designing the process, guiding the use of technology and conducting interviews and group discussion. Action research process enables free communication and aims to reveal various perspectives introduced by all participants. The research questions were set to serve the action and design research process and limit the phenomena researched.

The initiation of the process included mapping the possible and essential co-operative partners for research purposes. In the phase of ideation, the idea was introduced firstly to the nurses in the Clinique of Nephrology in Helsinki. Exchange of thoughts took place and supportive and realistic feedback was gained. The information gained was relevant due to their professional understanding of which organizations would be interested to support and possibly be partners in the research process.

Laurea University of Applied Sciences supported by providing firsthand knowledge of the use of teleconferencing technology with elderly customers and supervision. Participation to various projects concerning eHealth was enabled for the researcher. However, these were supportive experiences towards guiding and planning this research process. Kidney and Liver Association Musili, Finland was approached during spring 2010 and a meeting to initiate co-operation for research purposes took place in August 2010. Co-operation was agreed upon and voluntary participants for research purposes were found through Musili and their contacts in local associations.

Assessment of technology providers was carried through for the research purposes. Teleconference technology providers were contacted, met and negotiations of the costs for the research. This took place in May 2010 and September 2010. Due to the expensive costs of the teleconferencing technology and their services, Skype was used and found to be the most suitable for research purposes.

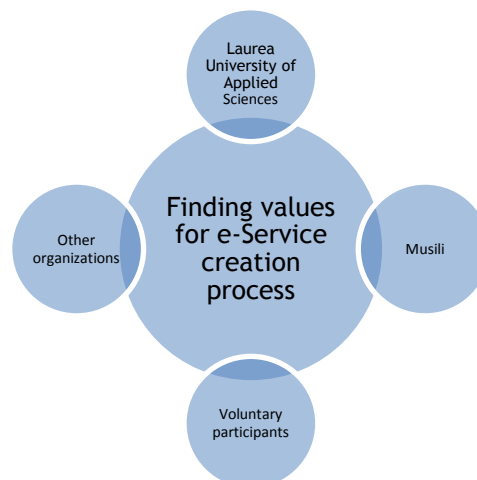


Figure 4: Participants involved in the research process.

Co- operation of various partners was essential and careful assessment of their interest towards the process done. The Kidney and Liver Association, Musili’s support was essential to reach the target group. The number of volunteers was hoped to vary between 3-9 persons. Six individuals were reached, of which five wrote short stories. One, ad hoc, next of kin participant was interviewed individually and three target group members. One volunteer was unable to participate to the research process and three dropped out after writing short stories. The final number of participants was three and the next of kin. The following sub- chapters describe the process in detail.

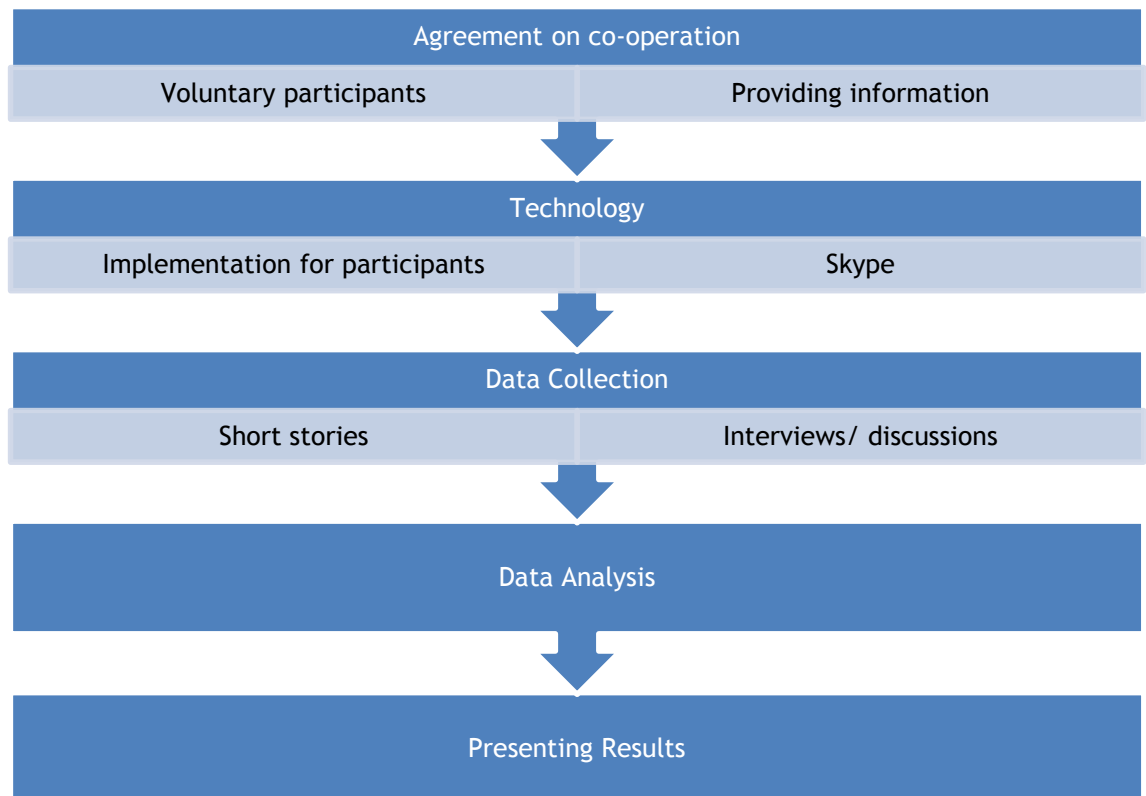


Figure 5: Stages of research process

4.2 Qualitative Design Research

As the research process aims to find out values of the target group research methods were assessed carefully to avoid leading the participants towards expected results. Shedroff (2003, 157) describes design methods to be more flexible, enabling creativity and openness in the design process. This research is part of service design process but not focusing on the service design itself rather aiming to find the core e.g. values of the users of the service. Shedroff describes several methods that can be used to create knowledge of user understanding; one of those methods is “dreams”. He describes as follows:

Another approach to understanding users and other audiences' emotional and social levels is to use dreams as a way of allowing them to indirectly disclose issues important to them. The indirection is critical because, when dealing with social and personal issues, too much attention paid to the process (or direct inquiries) often lead to phony results (2003, 158).

To avoid gaining inadequate and unrealistic information of expectations the voluntary participants were asked to write a short story in a form of a dream of their daily life. These short stories were analyzed by using qualitative content analysis.

4.3 Abductive approach

The research approach is abductive due to its social meaning approach of finding individual values. An abductive approach is used as a strategy in the interpretivism studies to understand individual concepts, motives and perceptions. Abductive approach enables many levels for interpretation and leaves room for understanding of unknown phenomena of social behavior. It is the approach that interprets rather than guides individual behavior. (Atkinson: 9.10.2010). In this context the abductive approach is justified, because there are no underlying studies to reflect the values upon eService creation process for the target group. Abductive approach is often referred as the "logic of discovery" and seen in need of a strategy (Paavola 2004, 267). In this approach strategies are seen vital because of its weakness in inference (Paavola 2004, 268). Therefore the phenomena should be studied in relationship to several other phenomenon and theoretical framework (Paavola 2004, 267). This means that an "investigative" approach alone, need supportive theories, in order to reflect and explain.

4.4 Data Collection and methods for analysis

In this research multiple data collection methods were used e.g. Short stories, Skype interviews. Reflexive diary supported the online phase as a log or a note book to keep the process together. Due to the chosen research approach qualitative content analysis was used to gain more profound understanding of the data. The short stories and interviews were aimed to gain individual understanding of the participant's values. Schemes rising from different stages of the data collection and through data analysis; grouping; similarities, connections and variables were analyzed. Gray (2009, 500) defines content analysis:

... the making of inferences about data (usually text) by systemically and objectively identifying special characteristics (classes or categories) within them. The attempt to achieve a measure of objectivity in this process is addressed by the creation of specific rules called criteria of selection which have to be established before the data can be analyzed.

The research approach is abductive and therefore connections and analogical thinking was used. Maslow's theory could be seen as the ground for theory for exploring and reflection of the results. As in all action research processes and qualitative studies, overlapping was taken into consideration.

4.4.1 Pre- online phase

The initiation phase started by co- operation agreement with Musili. The agreement was reached through sending the research plan prior to the meeting and a meeting with the head of Musili and one local representative. Voluntary participants for this research were reached through their contacts. Location of the participants was irrelevant due to internet based quality.

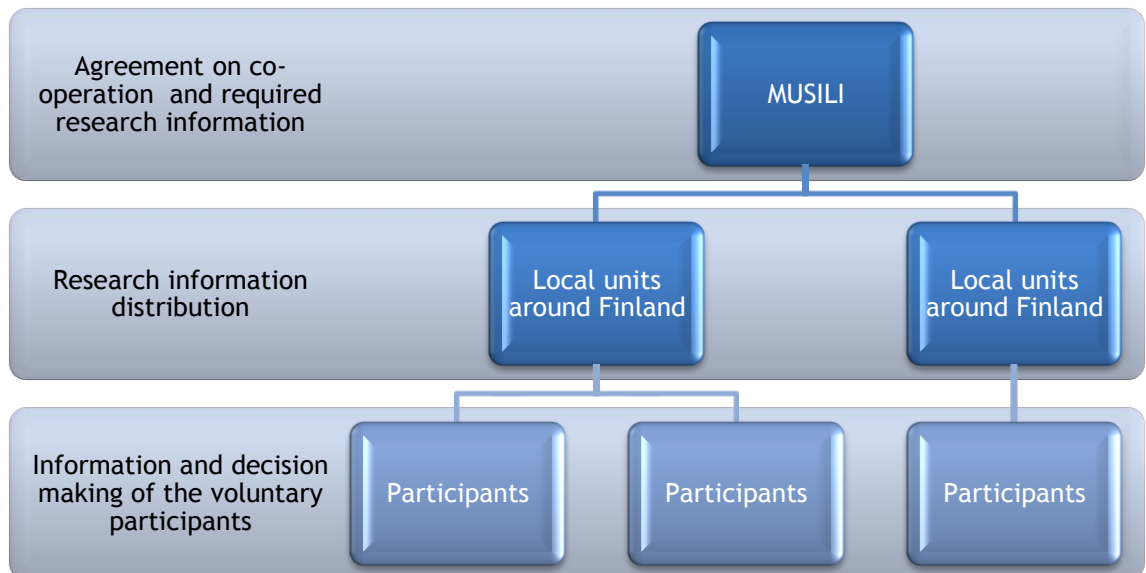


Figure 6: presents the process of reaching target group

At Musili's request a marketing letter (APPENDIX 1) and A4 information paper (APPENDIX 2) of this research was sent on the 14th of September 2010. Marketing letter was forwarded to the local MUSILI representatives and through their contacts 6 voluntary participants volunteered for the research process. Research address was created for contacts and was astel-care@gmail.com. All participants were contacted via e-mail to confirm their participation.

After confirmation from the participants, an assessment of technical equipment was carried through via e-mail. At this stage the decision making over technology was still an ongoing process. Assessment of the technology included:

- the speed of the internet connection (ADSL/ SDS)?
- what type of computer is in use (PC)?
- is there a web camera attached to the PC or a separate one?
- is there a microphone or a separate head set in use?

Teleconferencing technology providers need to know basic computer qualities in order to make decision of what kind of possibilities could be utilized. However, in this case Skype was available and easily accessible, also with a feature of group calls with video feature.

Participants received an e-mail (APPENDIX 3) that has those questions after their contacts had been confirmed. Also the participants were informed that the decision over technology had not been made and that the following e-mail would present the research process (APPENDIX 4).

The technology planned initially for use was high quality teleconferencing technology that enables phone calls via internet with pictures. However, the question was: if participants do not have web camera and are not willing to purchase one, the communication should be carried through low cost solution that doesn't demand investments. Therefore consideration towards Skype was initiated. It is the cheapest technological solution for teleconferencing at the moment. Skype does not provide the most secure calls but enables communication through internet without any costs and is easy to use.

Timing was assessed and while a final decision of the technology was being made; the participants were asked to write a short story in a form of a dream about their daily life. This analytic induction phase was conducted in order to find out if the research questions were consistent (Gray 2009, 495). Analysis of the short stories and interaction was carried throughout the whole research process to gain the most reliable results for the purpose of service design. If, however, the induction phase presents deviations the hypothesis of the process has to be re-evaluated (Gray 2009, 495). Participants were given few days time to write the story and e-mail the story to the researcher for pre-reading and analysis.

4.4.2 Online phase

Online phase started by the assessment of technical equipment of the participants. At this stage a decision of the technology was still under assessment, however communication via e-mails was going on. 5 of the six voluntary participants sent short stories of their daily life. And researcher read through the short stories few times to identify general themes. Those general themes guided the following Skype discussions.

Skype discussions were conducted during one week period. Times were set according to respondents' availability to be online. Request to tape the interviews were asked prior to Skype calls. Three target group members were reached through Skype as well as one next of kin,

who volunteered to participate. Discussions were unstructured, however, the respondents were asked to respond shortly to the general themes that came from short stories, and those were:

1. Work
2. Relatives/ Friends
3. Leisure time
4. Food
5. Illness

The conversations were open discussions. The duration of individual and group interviews was planned to last 10- 30minutes. Recorded conversations were typed out and analyzed by using qualitative content analysis methods. Respondents were also asked to consider a name or a theme that would describe their situation. The reason for this was to explore names and idea- tion for the eService. The results are presented in Chapter 6.

4.4.3 Feedback of the interviews

After the online phase and Skype discussions participants received an e-mail after few days for feedback. They were freely asked to express their experience. They were also informed about the process, research timing and that the final research is published and available in Laurea University of Applied Sciences database Theseus. The researcher also agreed to inform the respondents via e-mail about the results and progression of the whole process.

5 Data analysis

The chosen data collection methods: short stories, individual Skype interviews and group in- terview provide a multiple set and up to date data from different stages of the research process. Triangulation is a way of collecting data in multiple ways (Gray 2009, 417). Triangu- lation is a word drawn from the world of surveying, where measurement is taken from three or more different points in order to identify a particular area with accuracy. Elo & Kyngäs (2008, 3) define content analysis:

Content analysis is a method that may be used with either qualitative or quantitative data; furthermore, it may be used in an inductive or deductive way.

Due to the abductive approach of the research qualitative content analysis method was fit to guide the data analysis process. The number of respondents varied throughout the process. In the initial phase there were six volunteers. Five of them wrote short stories. Three CKD pa-

tients participated to Skype interviews and one ex- tempore next of kin participant. The results are presented in Chapter 6.

5.1 Data analysis of short stories

The respondents were asked to write a short story of their daily life in a form of a dream (1-5pages). Five of the respondents wrote the stories. Data analysis was carried through in three major levels and each included two phases of processing the data.

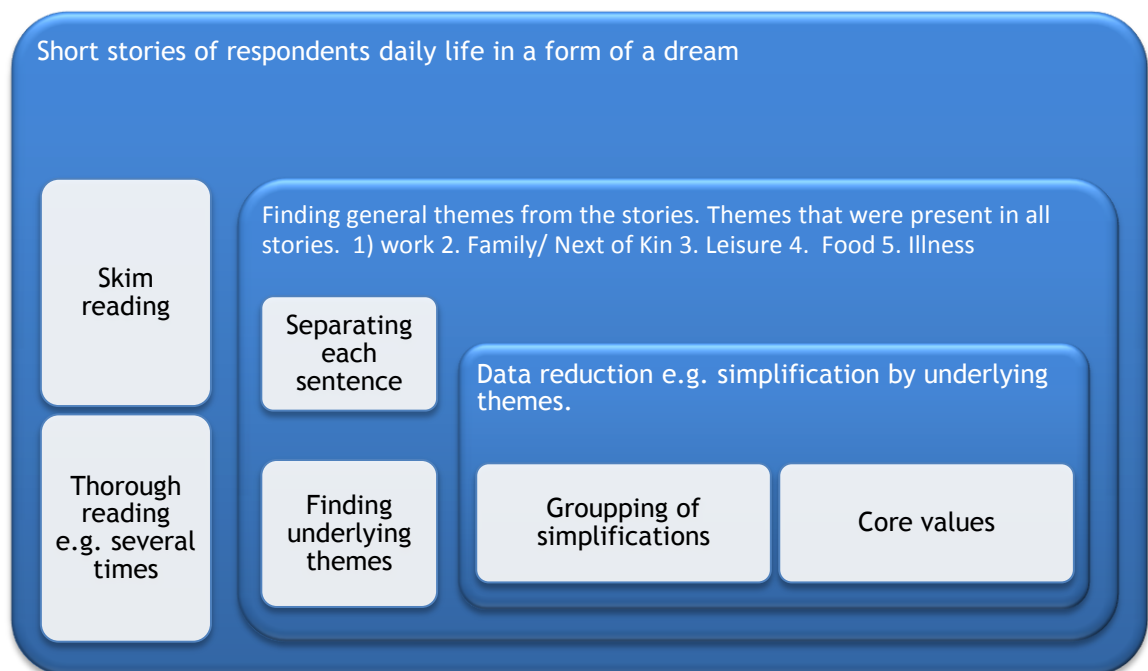


Figure 7: The stages of short story analysis process

a) The short stories were skim read to create an overview of the story content. b) The stories were read three times carefully to assess the thoughts from the skim reading phase. c) Five major categories were identified to guide the Skype interviews: 1) work 2) Family/ next of kin 3) Leisure 4) Food 5) Illness. These categories were not analyzed any further. d) The stories were separated and every sentence cut out from its context. e) Then the sentences were numbered and analyzed separately using open coding method. f) Each sentence was simplified to underlying themes g) Grouping of the simplified themes was carried through and results present the core values.

5.2 Data analysis of individual Skype interviews

Individual Skype interviews were tape recorded and typed out directly after interviews. Texts were cut into paragraphs and analyzed in the similar manner as short stories. However, differentiation was made due to the type of data. Short stories contained pre- thought sentences

and the structure of the data was different. Interviews were unstructured and guided by the situation and individual responses by the participant and researcher. The respondents were asked to answer to 5 general categories with one word, and the words were grouped under the general categories obtained from the short stories. These words were descriptive and are presented as a separate data box in Chapter 6. Discussions were guided through the onset of the five categories and respondents reflection upon values. The interviews were separated and cut into paragraphs. Grouping method was based on underlying themes.

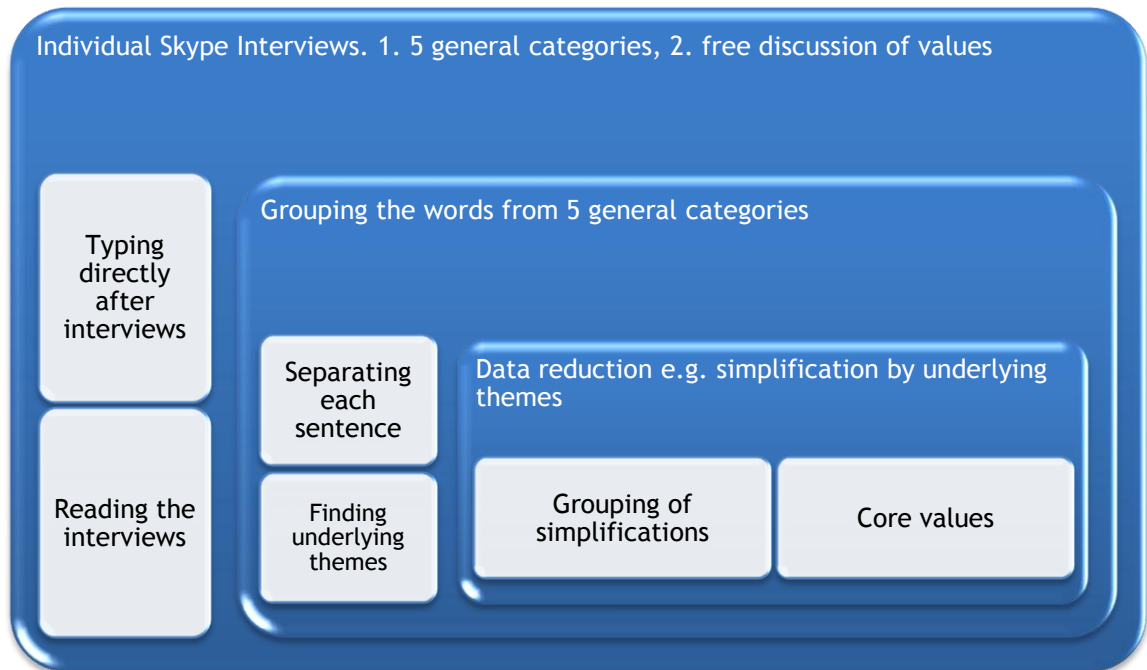


Figure 8: Individual Skype interview data analysis process

5.3 Data Analysis of group discussion

The group conversation was conducted according to participant's possibilities to participate. The conversation was tape recorded and typed out directly after the call. Discussion was mainly unstructured and lead by the researcher according to the flow of the conversation. Pre- planning for the conversation was based on the 5 categorical themes that were gathered from the short stories. The approach for analysis was data driven qualitative content analysis.

First part of data analysis was to skim read the conversations several time and to continue reviewing the data in a more profound way as follows.

Second part of data analysis was to define roles in the conversation. Two of the respondents were women and one male in addition the researcher. The researcher was named R, Male respondent 1, Female respondents 2 and 3.

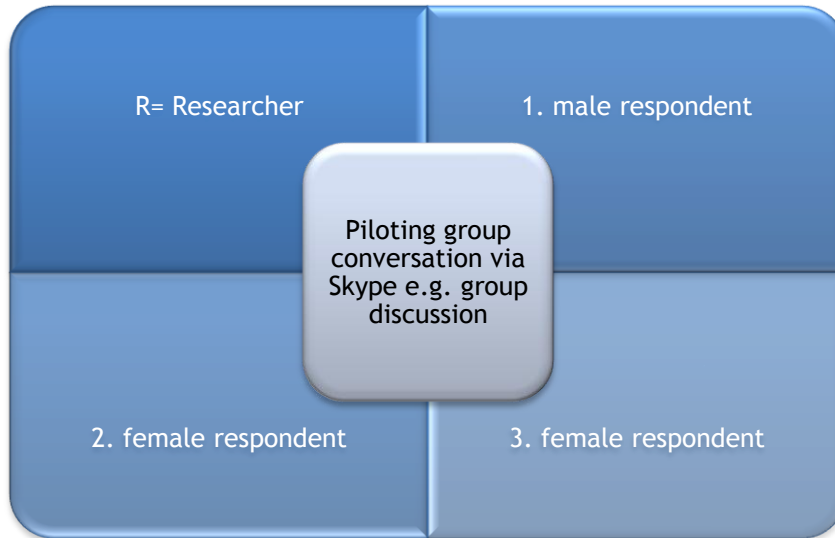


Figure 9: The role division of group conversation

Third part of data analysis was to identify how roles were taken in the conversation. Was it led by the researcher or were the respondents guiding and leading the conversation. Fourth part was to observe reactions in the conversation as well as do the respondents ask for clarifications in conversation and what are those clarifications asked for. Fifth part of the data analysis was to clarify the flow of the conversation see Figure 10. Sixth part of the data analysis was to group themes and phenomenon according to the context those were discussed. The approach for grouping was carried through from the perspective of the theoretical framework and results from the short stories and individual interviews.

5.4 Reflexive journal

The reflexive journal was kept by the researcher throughout the interviewing phase of the data collection. Due to background in nursing it is necessary to note that researchers understanding of the CKD, from professional perspective might contribute to objectivity of the process. The reflexivity understands that the researcher is not an objective observer, or neutral observer, rather plays a significant role in knowledge creation (Gray 2009, 488).

For this research the journal was designed for the interview phase, due to time challenges, as a log of events. Some reflection upon phenomena's were noted, which are presented in the discussion part. The log wasn't reflected upon values, due to its technical detail of reporting times and construction of the process.

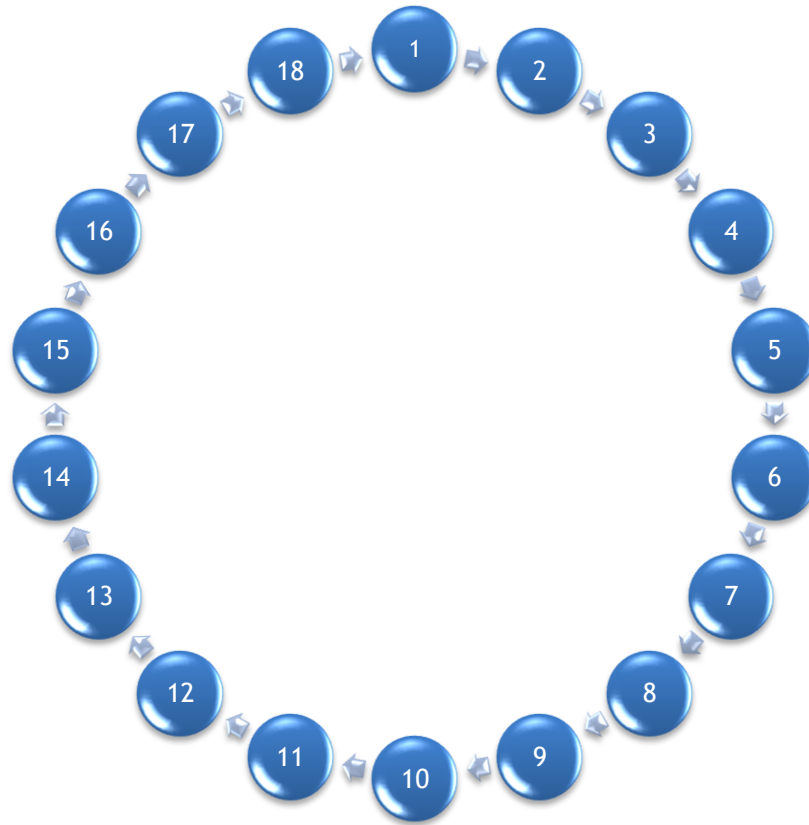


Figure 10: Flow of the group conversation in numbers

Firstly the researcher made a Skype call for the participants by choosing their Skype names into the group and pressing “call”. Second phase, the researcher assessed that everyone is present and can hear each other. Short introduction was made to the respondents, especially to respondent 1, who had not been interviewed individually before the group conversation. Third step was to provide information of possible technical challenges during the call, and how to proceed if the call cuts off e.g. the researcher make another call. Fourth, and already a conversational part was asking and receiving information from respondents 2 and 3 of the individual interviews. Fifth stage was to slightly lead the topic towards themes that had raised from the short stories e.g. 5 major categories. Sixth step was lead by the respondents towards peer communication of their ongoing treatments. The flow of the conversation was natural and the lead was taken by respondent 1 by asking questions from the other two respondents. Seventh step was to let the conversation flow, the researcher was in a listeners or observers role, by not interrupting the respondents lead towards individual situations and experiences. The stage eight was a stage when rather personal and difficult life experiences were shared by respondents and ninth step was in sharing similar experiences about the CKD. At the tenth step, consideration of family values and support of social networks were discussed, at this point the researcher was in a supportive part of the conversation. Eleventh step lead to limitations of CKD by the researcher and participants shared freely their though-

ts. At the step twelve individual CKD histories was reviewed, at this part the conversation went a bit more on an in depth level then in the first stage of sharing similar experiences. Stage thirteen was sharing very deep personal disappointments in the cycle of CKD by one of the respondents. At this stage, the researcher decided to guide the conversation towards a different direction to maintain respondent's safety of not getting hurt or upset in any way. The direction of conversation was lead by the researcher in the stage fourteen to the topic of nature; environment and descriptions of important elements of nature were described by the respondents. Step fifteen was initiated by the researcher of internet and how the participants utilize services through internet. Stage seventeen was to conclude the conversation by a question of how the respondents would describe their life situation in one word. They were guided to send the themes or words via e-mail. In the final stage, eighteen, the researcher provided information of how the research process proceeds and reminded that the results will be published in Laurea University of Applied Science's data base.

Skype software worked without any problems and was found easy to use by the participants who had not used it prior to the individual interviews. The layout of Skype enabled easy understanding of which person was talking, even without video feature.

6 Results

This chapter presents the final results of core contributors to values and values obtained from the data analysis process of data: 1) short stories 2) individual interviews 3) group interview. Precise grouping of each data collection phase are in APPENDIX 5 due to readability of the thesis. The analysis results were reviewed carefully and similarity from all data sources was identified. Due to that the core sub groups have been combined and the meaning of each value has been presented according to themes from the data. Evidence of underlying thoughts from raw data is presented to support the analyzed data of each value. The values are separately reflected upon the theoretical framework in Chapter 8. Core values are presented in a random order, and are not classified in the order of an importance. Five core values were identified. And the sub categories of how those were derived are presented and quotations from the data provided to support the findings. Original quotations are presented in APPENDIX 6.

6.1 Responses with descriptive words to five major categories

Illness:	Work	Leisure	Next of Kin	Food
Controlling	Important	Exists and doesn't exist	relatively small group	Important
Acceptance	Maintains life	Sports	Important people	Tasty
enemy	Lost	Important hobby	Most important people	Sweet
Adapting	Meaning of life	Finding time for it is a skill	Wife, son, three legged chair, Faith, connection	Pleasure
Passenger	Shared responsibility	Free choice	"Front row"	
Necessary evil		Moderate		

Figure 11: Descriptive words from 5 major categories

To provide initiation for the individual interviews five major categories were used. The respondents were asked to reply with one descriptive word to each category and results are presented in Figure 12.

6.2 Five core values or contributors as final results

The five core values are defined to the underlying needs and themes that were derived from the data. Overlapping, meaning similar themes came out in the data analysis process and from seventeen sub- categories the conceptual core values were clarified into five main core defining core value areas.

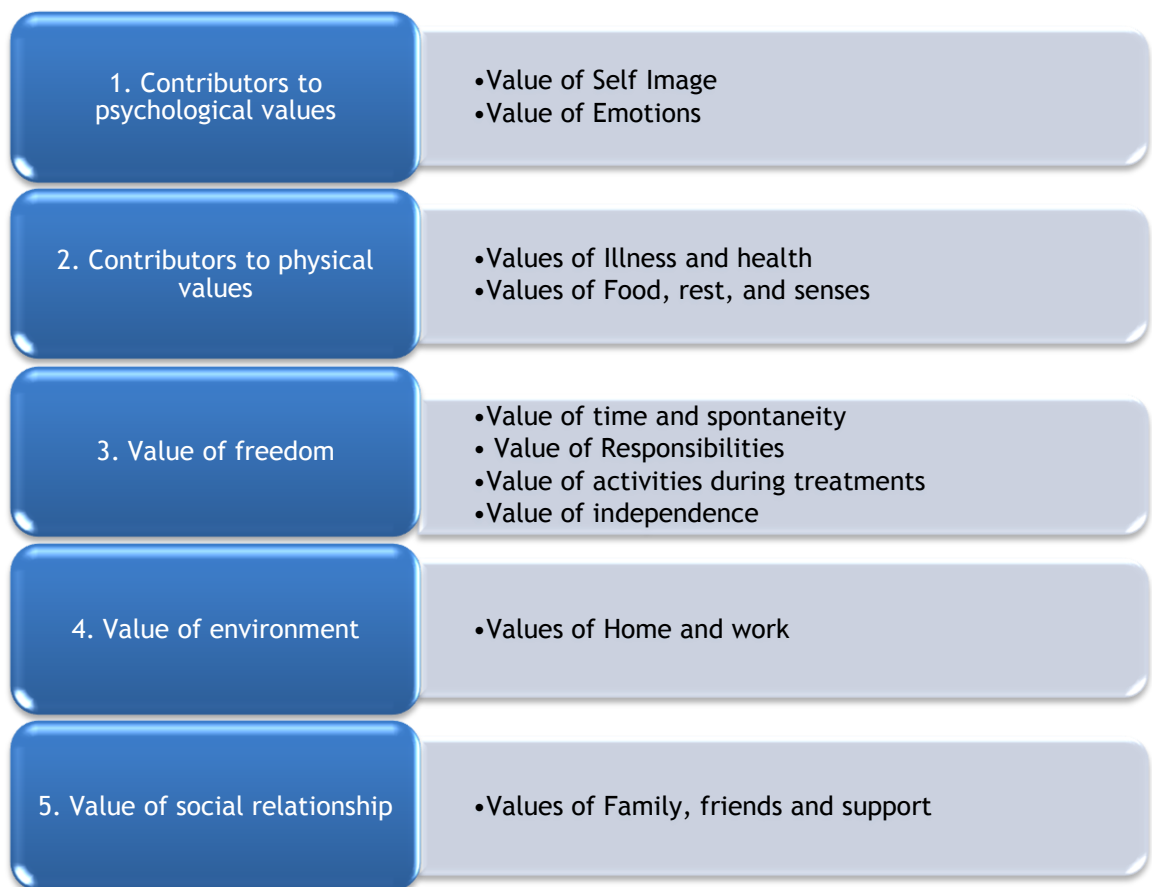


Figure 12: Core contributors to values and values obtained from complete data analysis

6.3 Contributors to psychological values

All stages within the five defined core contributors to values have an effect to psychological well being. From the data self image and variety of emotions were derived. Emotions linked to all areas of life as well as most positive areas of life that was emphasized by the respondents to be social relationship and support network. Self image and emotions were the main categories for defining psychological values.

6.3.1 Self image

Self image was seen affected by the medications, insertion of catheter for dialysis. It was strongly linked to the disease. Self image was reported to affect to sex life.

I look at myself in the mirror and automatically turn my head. What I see is not pleasant. My face and body are swollen. Skin is dry and hair growth is horrible. I look tired and sad. Make up would only make me look like a clown. I'm distressed.

After the insertion of the dialysis catheter he (boyfriend) took for granted that sex life would continue as it had been. But the catheter was too big of a deal, I could not feel relaxed. We still have sex, but rarely and then it is kind of unpleasant. Gladly our relationship is on solid grounds. (j)

6.3.2 Emotions

Respondents expressed number of emotions, linked to personal life and events contributing to them. The list of emotions is presented in APPENDIX 6 thoroughly. The meaning of family through emotions was the enjoyment of family.

I think about my life, that could it be any better. Wonderful husband. Has been on my side for almost twenty years. A son. Disabled and autistic, but the dearest of all. I wonder what battles we have been through. And that everything is fine now. I wonder how new challenges start for my son, when he gets to go to his own new home and how it will take time to adapt. I think I don't fear what is ahead. We have survived all so far and we continue to. (k)

6.4 Contributors to physical values

In all data CKD respondents did not mention anything about health. The word that was in use was illness. Only the one next of kin member spoke about health. That respondent's view was that illness is a "necessary evil", however to the illness within family the response was "acceptance". In the second stage of short story analysis, the number of separated sentences was greatest in the group if illness. Overlaps between diet and illness occurred repeatedly. Two of the respondents didn't view themselves as ill as one of the respondents, whose process with the disease had a lifelong history. The onset of the illness for two other respondents had become later in life. The two respondents carried out the treatments at home and one respondent at the clinic.

6.4.1 Value of illness and Health

Illness was viewed as a “passenger” or accompanying partner. Many daily actions were mentioned to be scheduled by the treatments.

AK96, no, it is not a gun from our Eastern neighbor. It is the Western neighbors design, Gambro- dialysis machine. Almost the size of me and heavy as me is the fifth member of our family, in addition to wife, child, dog and me. Relationship with AK 96 is close, unfortunately it can't do without me and I can't do without it. Anyway, again it's 3h quality time with the bloodsucker. (u)

I have been in the treatments for years, so those are a part of my life. Loosing eye sight I need assistance in daily activities. After the beginners' difficulties, I learned to notice that I learn new every day. (u2)

6.4.2 Value of Food

All respondents mentioned food in their short stories. It was linked to pleasure and satisfaction. CKD causes restrictions to diet. Respondents repeatedly mentioned food and restrictions. Irony towards diet was present also. Shopping food in grocery stores was also viewed from two different perspectives. To a family, who had an autistic child, it was a rehabilitative event. To another respondent grocery store visits were time consuming and difficult because of CKD and the need of assistance. However, eating was seen as a pleasure and a social event.

We come home from a long walk and have lunch. Brewed soup tastes delicious after a long autumn walk. (a).

Next we shall go to the food store, which is always difficult. I have to wait for my mom who helps me carry the bags. That is prohibited from me, unless I want a meter long hernia. At the store, we spent time. Mom is trying to lose weight and I am not allowed to eat products that contain phosphorus and gout also limits the diet, so shopping is difficult. I look at the chocolate department, but that is especially denied. Gladly, vegetables are allowed. We end up making vegetable soup. I have always enjoyed food, so slightly one sided diet bores. (b).

6.4.3 Value of Rest

Sleep was a topic that was present in the short stories. Rest and especially sleep was considered as a significant matter, if it was natural and deep.

At the end of the day I note that I am tired. However, a new moment of excitement is present, will the sleep come or does it come with Sifrol (medication)? Sleeping with Sifrol is kind of like sleeping with Johnny Walker. Chemical sleep is not very refreshing. (l)

I wake up feeling fresh in the morning. I have slept a whole night without waking up. My husband sleeps tightly besides me. I don't dare to wake him up. (m)

6.4.4 Value of Senses

Respondent who had lost sight (u2) mentioned learning to be part of adapting. Senses referred to the eye sight and coping in daily life, it was strongly linked to communication. Various skills and respect towards them were reported.

Skills with hands have become important to me and I respect them a lot. I have to do a lot with my hands, feel and take contact to other people. (v)

6.5 Value of Freedom

Time and spontaneity was viewed from few perspectives. Four seasons to history, age and cycle of the days. However, the meaning of time was emphasized in different contexts. Freedom as such was something that each valued: freedom of speech, freedom to make individual choices and freedom to fight for rights. However, spontaneity was something that all respondents felt lost, even the next of kin.

6.5.1 Value of Time

Respondents reported that routines and scheduling is a necessity due to CKD. The use of time, when doing treatment was seen as "killing time". However, the time in the treatments was not seen as a waste of time either. Rather as a necessity in daily life.

...about a year ago, before beginning the treatments, I was exhausted, so exhausted that I practically slept when I got off from work and dialysis unit, I was so exhausted, that I used the whole time to it, slept 2-3hours, so that I could function normally. After I had been in dialysis for couple of months, I was clearly in a better shape; therefore I find the time spent on it rather insignificant, because I have the motive, that if I would stop the treatments how bad shape I would end up to. (c)

During the treatments I read e-mails, take care of financial things in online bank, and the time is spent on "killing time"(d)

...to me spontaneous acts have been really important in many things. Now it is very limited, of course. With these treatments and dealing with them, takes time and planning, it effects to the type of doing what would want to do. (e)

6.5.2 Value of Responsibilities and Duties

Work was seen as a responsibility as well as children. A duty to go to work was seen as part of carrying individual responsibility to the society.

We have autistic son who needs a daily structure so either one of us is the nurse. It's nursing job. (r)

Work: duty of life, way to carry shared responsibility. (s)

6.5.3 Value of activities during treatments

Respondents described several activities that they do during treatments. Those carried through treatments were all activities that could be done while sitting down, such as watching TV, being on the internet, handcrafts, reading and listening to music or radio. Other important hobbies were related to sports, swimming, cycling, culture and arts and pets.

I watch TV while sitting and doing dialysis treatment. It has become my new hobby. Now there comes master's and dogs training school, which I like to watch with interest. I am trying to get tips for my dogs training. I have been in a better shape due to the treatments so me and the dog went to clicker training. (p)

I stand up and head to "bagging". I drain at the fireplace room, fluids go back and forth and I listen to Raimo Pollari's collection from Iskelmäradio. (q)

6.5.4 Value of freedom and independence

Spontaneous was reported to be lost due to the onset of illness. Not entirely, but time scheduling and freedom without routines was reported to be affected. Freedom of speech, choice, thought and action were determined important, although action was somewhat distant.

Spontaneous is gone, learning this has been challenging, because I have been extremely spontaneous 16 years ago. Also child's illness has been hardship. (u3)

What would I do with total freedom? It is an illusion; I can miss it and dream of it. (u4)

Freedom is a big value, important, personal freedom; independence and genuine independence. Sets to the highest of value hierarchy, I am an individualist. (u5)

6.6 Value of the Environment

Atmosphere was important to all participants. Home, coping at home and events in the environment were seen to be contributing to emotions and activities. Home itself was specifically defined by one of the respondents. Working environment was also described.

I could not live in a home that would not have any colors; red, blue, violet, and green. Flowers are important to me. I notice dust on leafs and I wipe them. It feels like they are pleased. They lift the leaves and look greener than ever. (n)

At the office, I note that there is a 25% possibility to insert the right key, out of two, to the lock. I manage to enter the office and change clothes. I open the computer and phone and eat yesterday evenings bread, which partially has melt inside the plastic cover. (o)

6.6.1 Example of traffic

Traffic was stated in short stories from the perspective of environmental surroundings. Driving and driving skills were mentioned.

My car is willing to start, but not willing to run. I have to tease the old thing several times. I back up the car off the yard while it makes screaming noise. Morning traffic is usual, although there is always someone who could have stayed at home. (t)

6.7 Value of Social relationships

Social relationships included all important human interactions, friends, relatives, family and pets. Support and help were the defining factors in this value.

Our friends drop in on their walk. It is nice to see them again. We drink tea and talk. We think about health and illness. Joy and sadness. We talk about our children. Their joys and sorrows. We remember summer. We enjoy each other's company. We thank some higher force for giving us friends. We laugh at that, because none of us belongs to the church. (f)

My boyfriend calls and tells me that he gets off the army for the weekend. I'm glad, because support of the loved one has been significant always. In a sense, duty to go to army came at a bad time, because I would have needed him to support me at home. We live together, but weeks I live with my mom, because I need help in many things. (g)

6.7.1 Family and Next of Kin

Importance of family was present throughout the data. Respondents emphasized the meaning of belonging, children and trust around them. Family was seen as a unit of support.

Son, husband and family. Family is extremely important, glued triangle. Some kind of safety and commonness. And being a member of an unit is vital to me. (h)

Even though days are hard and often strengths is lost, I still feel happiness. My family supports me mentally and physically and I have a strong group of friends.(i)

6.8 Concluding results

Due to variety of data, multiple similarities were obtained from it in the data analysis process. The five core results came through the reflection of needs of underlying medical condition as well as through the repeated themes that respondents provided in the data. Data analysis process as such resulted into similarities and grouping was relatively natural when considering underlying theories. CKD restricts life and emphasis of values may shift change from an individual perspective towards more family related and support respected daily life.

7 Discussion

Timeframe for this research process was relatively short, only three months. Limitations to time, contributed some challenges in data analysis and conducting the research. However, use of internet was easy and fast. The emphasis was on initiating thinking process of values for the participants and gaining trust of the participants and also insight of contributors to the values. Ethical issues, trustworthiness, discussion of findings as well as challenges within the research process are discussed in this chapter.

7.1 Ethical issues

Research was based on voluntary participation and the respondents were allowed to determine their participation at any time. The process was an experimental research and the research through support for eService creation process, and the eService itself aims to support well being of the target group. The process was intended to be enjoyable and not harmful to the participants. Confidentiality was maintained of participant's personal details e.g. names were deleted, other identification data was not collected apart from e-mail and Skype names. Data used for the research purposes is destroyed after the final reporting. The whole

process was based on collaboration and participation which created a safe and continuous assessment for participation to this process.

Respondents underlying medical details or identification numbers were not asked, only an e-mail address for confirmation of participation to the research. In this paper, respondents cannot be identified and the researcher has made sure that information obtained from data collection is separated from the underlying contexts of texts or discussions. Information gained for the use of research purposes was clearly stated to the respondents beforehand and also before publishing the results. This document is public document and if any respondent would have denied the use of obtained data, the data would not have been used in this research.

Due to the characteristics of social and virtual media participants voluntarily discussed delicate and personal matters and were not forced at any point to give any information. The researcher withdraws from all responsibility and knowledge that the respondents have given and are presented through data analysis process. The process as such was positive and participants were motivated to be involved, which has brought contentment and open approach for conducting the research.

During online conversations, researcher made sure that certain behavioral etiquette took place, which came naturally from the respondents. Notifications towards respectful behavior were unnecessary. Individual privacy and respect was seen as a ground value for conducting the whole research, the respondents respected each other in group conversations and were supportive and understanding in sharing their experiences. Unexpected ethical issues were not encountered during the process during careful assessment of how conversations of values were kept together, as well as sympathetic attitude towards peer participants.

7.2 Trustworthiness

The data collection process was designed to gather data from multiple sets that contribute to validation process. Validity in qualitative research is often under debate. In this case the combination of three different methodologies 1) short stories, 2) individual interviews 3) group interview provided a reasonable amount of data of the area of research. This method assured a full and rich data; triangulation. Same themes were repeated in the data collection process.

In the first phase when respondents were asked to write a short story of their daily life in, a form of a dream; an initiation process of thought was implemented. When writing a story, thinking is structured and, in general, carefully assessed. The aim of the short stories was not to direct the respondents to explain their values, rather to explore and use imagination. The benefit of this was that respondents were free to write what they wished. Short stories were

well written, with a deep individual insight. However, the given task “writing a story in a form of a dream” could contribute to reliability of facts in reality. The researcher did not need or want to know if the stories were based on actual reality or to a dream. This could be seen as a contributor to reliability; however, the approach of design research is to allow use of imagination which aims to the research purpose, to support eService creation process, which is innovative and free of research limitations.

In the second phase of data collection, the individual interviews were unstructured. Guiding topic were values and participants own reflection towards their daily activities. The five major categories which respondents answered in one word, aimed towards descriptive and spontaneous answers. An instant answer provided an open and slightly fun twist to the interviews. Individual interviews also provided privacy and more in depth conversations; a phase of getting to know the respondents. To some extent the process of thinking had evolved and respondents maintained the conversation clearly within the topic.

In the third phase of data collection, group interview, the conversation was unstructured. Allowing the respondents to interact and share thoughts freely. The researchers’ role was slightly more observing, only few guiding questions were presented. One was in a situation when the conversation flow was on sensitive health related topic that could have ended up in distress for participant’s perspective. Deep disappointments in life due to CKD could have brought out sensitive issues; therefore guiding the conversation to another direction was indicated. Two of the respondents, who had been interviewed before the group interview gave new ideas and names of descriptive themes for the life situation. One was “The Cosmic Upset”. In the end of the interview respondents were encouraged to contact via e-mail if thoughts concerning the research and values evolved further and they wish to share it.

Trusting relationship towards the respondents was reached through continuous communication via e-mails. Explanation of the process, the stages of the research and guiding directions of downloading the Skype for research purposes created an open and learning environment for all involved. In the beginning of Skype interviews the respondents were informed that some technical problems may occur and that millions of people were online at the same time.

The results present similarities from all collected and analyzed data, which refers that the results are rather accurate and not a methodological artifact. The consistency of maintaining the conversation in values and initiating the process of thinking before the interviews contributes to the reliability. Benefit from the researchers’ nursing background enabled understanding of knowledge of the target group. Understanding information linked to illness and understanding the process and stages of it affected to the data analysis in a positive way. If the researcher would have not had any prior knowledge of CKD patients, the connections and phenomenon could have brought a dimension of unreliability and distention of time frame of the knowledge creation purpose.

Considerable emphasis for conducting the research in a short period of time was in the enabling technology; computers, internet and Skype. Communication was done on real time and fastness of sending e-mails and setting up Skype call dates was effortless. The researcher also had the possibility to guide the respondents via e-mails when installing Skype, give advice and correct any misunderstandings of the process.

7.3 Discussion of findings

The purpose of this study was to assess values on the reflection to Maslow's hierarchy of needs of the chronically ill kidney patients and their next of kin. The methodology and data collection was aimed to serve the purpose of the research; to support eService creation process towards customer oriented approach. Therefore, design research method; short story telling enabled an approach without much technical guidance of knowledge of the respondents. Rather, to set their minds on thinking about values. Skype interviews were conducted within a one week period. Respondents were at their homes and researcher at any quiet location. The method of conducting research via internet, as mentioned previously, was enabling and flexible. Effortless and cost- efficient to all participants; there were no financial costs for this research. Skype installation was experienced easy as well as the use of it. Group conversations were easy to conduct and quality of the calls was relatively good. Safety e.g. confidentiality could not be guaranteed for the research purposes via Skype, even though Skype is considered as a secured service. However, all involved were informed about possible problems and participation was voluntary.

The aim of the research was to find out core values of CKD patients and their next of kin. Initially, next of kin members were not reached, but one respondents family member was willing to participate to an individual interview which was conducted ad hoc. Finding themes from stories was easier than from the interviews, due to structure of thinking process of writers. However, the interviews revealed similar sub groups and core values could be derived from those sub-groups, although, some of the categories were named as contributors to core values. It can be concluded, that the methodological approach, which enabled respondents to reflect freely, was successful. But to make the conclusion complete, the approach of the thesis was abductive and instead of making a single conclusion based on data, reflection towards presented theoretical framework is necessary in order to answer to the research questions.

In the literature review, Maslow's hierarchy of needs was presented. The data obtained in the research included a value of freedom and independence. However, spontaneity was absent due to CKD and limitation of time consumption. Maslow's hierarchy specifically reflects upon spontaneity in the self actualization part, that is the highest part in the hierarchy. Respondent's leisure time was affected due to CKD, or they had little or no freedom to act sponta-

neously. Scheduling and organizing time according to the treatments was stated several times. One of the respondents expressed changes in self image, due to medications and catheter insertion. In Maslow's pyramid, at the second place, is self esteem and self image. Also sexual life had been affected by the maneuvers due to CKD. Self confidence, inability to relax despite of loved ones accepting attitude, contributed to the self image and self esteem.

Maslow's third and middle section of the hierarchy states the need for belonging and love. All respondents emphasized the importance of family, relatives, friends, social relationships and love. One of the respondents clearly stated the need to belong into a unit. Fourth Maslow's hierarchy states safety. Safety as such is a multidimensional context and can be viewed from various perspectives. For the context safety is perceived from the perspective of security of the body. CKD was reported to create limitations and changes into body image. It has to be included that invasion of any kind, medical, violent or other is an invasion towards individuals self control. It can be assumed that invasion of medical interventions into individuals body, e.g. catheter insertion due to CKD, is a threat as well as the disease itself. Maslow talks about health property and definitions of health in the literature support the view towards individuals' need of being healthy and well fit. When an onset of an illness, in this case CKD the perception towards health changes; data analysis presented this from the initial reading of short stories. None of the respondents spoke about health, they spoke about illness. Also in the interview phase, the researcher asked from one of the respondents a question "weather internet grocery shopping would be considered easier?" the respondents reply was simply: "for us going to the shop is important social event, it is rehabilitation due to child's illness". The same phenomena occurred when interviewing ad hoc next of kin. The researcher asked "what does an illness mean to you?" the respondents reply was "unnecessary evil", however, when the question was rephrased to "what does an illness of the next of kin mean to you" the response was: "acceptance and coping". There clearly are variations between chronically ill perceptions towards health and a "healthy person". As mentioned in the literature review, some may argue that needs are not basis for values, but in the case of a chronic illness, daily life is highly restricted upon the illness. Therefore choices towards diet, sports or view towards independent will become into a new light of value, than before the onset of a disease. This can be difficult to accept, however, the focus of values seems to shift after acceptance of the situation. Two of the respondents were carrying out the treatments at home, which provide a certain dimension of freedom, whereas one of the respondents visits a dialysis clinic. Rest and sleep was one of the core values based on the need of rest, from data analysis. Maslow's hierarchy of needs, on the ground level and the basic need is sleep, homeostasis and excretion. To which CKD affects to; if the target group members were not ill, the need for treatments or other daily worries would not exist. The treatments are life maintaining and as data presents the time spent doing the treatments is not considered always negative.

Restrictions and limitations brought by the CKD were presented in the literature review, although from a more health care perspective. However, the results support the claim of restrictions affecting to daily life. The respondents described various actions that they can carry through while doing treatments. Those were TV, Radio, Internet, Banking, Discussion boards, reading, handcrafts and everything that can be done while sitting down. In the group conversation respondent 1 brought up internet's possibilities and discussion board. Respondent used those to gain information out of interest. The importance of discussion boards was presented also in the literature review. Patient organizations run discussion boards as peer support services and people seek information. Respondent 1 also noted that the quality of information varies a lot, which was also an observation from the literature. Most commonly used and already a utility good are the banking services.

What kind of values does the target group have? The target group has values that are based on human needs: family or next of kin, importance of support, self esteem and self image and the importance of those for love and bring belonging. Hobbies, time consumption; even though limited, entertainment and environment, skills and nature. The theoretical framework supports the results of the research, which contributes to reliability. One differentiation and a note to make, a value of freedom has a different set of limits due to responsibilities, scheduling and diminished ability to act spontaneously.

The second research question, what is value adding additional eService for the target group? According to the data, socially supportive site that would contain insight to content that provides information to and support in the five core value areas. The core values as such do not give a direct answer to the second question. Another research could be conducted to find an adequate answer. Also the data could have been viewed from the perspective of how values change within different data sources. This angle could have provided more insight to the way respondents thinking process of daily values evolves.

7.4 Challenges

For supporting eService creation process the findings can be used as underlying categories in an innovation process for service content. However, the actual content of service should be piloted in real settings with the target group, to gain valid user driven feedback from the implementation and for development. One major challenge is the fact that values might not be the right direction of approach it could instead be the needs or only one of the needs. Limitations of how the information could be used in service creation clearly have to be made. Because within the research process the use of technology was relatively easy, challenges for eServices are platforms and domains of how to construct a service that technically provides useful “playground” for the target groups’ utilization. From perspective of values and needs the challenge is in CKD’s different stages, the process evolves and fluctuates. Therefore it is necessary to have an understanding of the CKD patients and stages that they undergo. The next of kin perspective could be another study to conduct, to gain insight of their needs and values towards coping in daily life. A loss of sight of a spouse changes daily life from many aspects, and need and values surely change along. How to support, and provide help in an adequate way through online services is challenging, yet number of services is growing for the need of population.

To conclude, this research was a supportive research for eService creation process. The validity of the results can be viewed relatively reliable due to multiple data sources and similar results from all of them. Also, theoretical framework supports findings. The feedback from the respondents was complementary. The describing name that the participants were asked to think about was found: The lighthouse, presents hope and guidance even in challenging situation.

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FIGURES

Figure 1: Summary of the stages of kidney disease and treatment process. The lower boxes present related themes in all stages from social and behavioral aspects, the table is based on Oxford Handbook of Dialysis (2004, 18-106)	10
Figure 2: Maslow's hierarchy of needs	14
Figure 3: The time frame of the research process	17
Figure 4: Participants involved in the research process.	18
Figure 5: Stages of research process	19
Figure 6: presents the process of reaching target group	21
Figure 7: The stages of short story analysis process	24
Figure 8: Individual Skype interview data analysis process.....	25
Figure 9: The role division of group conversation.....	26
Figure 10: Flow of the group conversation in numbers	27
Figure 11: Descriptive words from 5 major categories.....	29
Figure 12: Core contributors to values and values obtained from complete data analysis	30

APPENDIX 1 Osana Iloisten asioiden edistämistä?

Kohtasin ihmisen jolla oli vaikeuksia munuaisten vajaatoiminnan diagnosoimisen jälkeen. Hän oli nuori, virkeä ja elinvoimaa oli riittänyt aikaisemmin kaikille läheisille. Sairaus toi mukanaan surua, yksinäisyyttä ja hankaluuksia selvitä arjessa perheen kanssa.

Kohtasin myös henkilön joka ei puhunut suomenkieltä. Sairaanhoitajana, tehtäväni oli aloittaa hänelle suunnitellut hemodialyysihoidot ja ohjata oman terveydentilan hallintaa munuaistenvajaatoiminnan kanssa.

Haasteita oli valtavasti, jopa kellotaulun ja ajan ohjaaminen oli vaikeaa. Piirsimme toinen toisillemme. Emme aina ymmärtäneet toisiamme, mutta löysimme sanattoman kielen kuukausien kuluessa.

Usein turhauduin tehottomuuteen yksilön arjen tukemisessa, päädyin hakemaan ratkaisuja ja opiskelemaan Laurea Ammattikorkeakouluun jatko-opintoja. Halusin lisää apuvälineitä joilla voitaisi edistää hyvinvointia. Tahtoa nähdä asiakkaiden todelliset tarpeet, ne asiat jotka tuovat hyvää oloa ja ylläpitävät elämäniloa. Auttaakseni ongelman ratkaisussa olen kehittämässä uutta yhteisöllistä etätukipalvelua munuaispotilaille ja heidän omaisilleen.

Mitä sinä toivoisit lisää hyvinvointisi parantamiseksi? Tule mukaan hauskaan ja seuralliseen luomistyöhön joka tulee jatkossa nostamaan munuaispotilaiden elämänlaatua.

Asuinpaikkakunnallasi ei ole merkitystä, tarvitset vain tietokoneen ja internet yhteyden.

Mukaan kehittämään pääset lähettämällä sähköpostia: astelcare@gmail.com

Terveisin: Sara Asteljoki, Sh, Master Degree Student of Health, Laurea Ammattikorkeakoulu, Otaniemi Espoo

APPENDIX 2 Arvopohjakartoitus munuaispotilaille ja heidän omaisilleen suunnatulle virtuaalipalvelulle

Tutkimuksen tarkoitus: on tukea e-Palvelun sisällön luontia ja arvopohjaa jolle asiakaslähtöinen e-Palvelu luodaan.

Tutkimuksen tavoitteet: on kartoittaa munuaissairaiden ja heidän omaistensa arvoja ja palvelun sisällön luontiprosessi yhdessä kohderyhmän kanssa virtuaalisessa ympäristössä pilotointijakson aikana syys- marraskuussa 2010.

Tutkimuskysymykset: 1) Minkälaisia arvoja kohderyhmällä on? 2) Minkälainen on lisäarvoa luova e-Palvelu kohderyhmälle?

Tutkimusmenetelmät: Tutkimus pohjautuu kvalitatiiviseen toimintatutkimukseen joka on osallistavaa tutkimusta. Arvopohjan löytämiseen käytetään tarinankerrontaa, joka on tavanomainen menetelmä kvalitatiivisissa etnografia- ja design tutkimuksissa. Kohderyhmähenkilöitä toivotaan olevan 3-9 ja tutkimukseen osallistuminen perustuu vapaaehtoisuuteen. **Tutkimuksen alkuvaiheessa (1)** kohderyhmän jäsenet kirjoittavat unen muodossa arkipäiväiset tapahtumat. Unien muodossa kirjoittaminen antaa vapauden myös kertoa toiveita. **Toisessa (2) vaiheessa** tutkija analysoi tarinat käyttämällä kvalitatiivisen sisällön analyysin menetelmiä arvojen löytämiseksi. **Kolmannessa (3) vaiheessa** kohderyhmän jäsenet ovat virtuaalisessa palveluympäristössä telekonferenssiteknologian kautta ja luovat yhdessä palvelulle sisältöä yhdessä suunnitellun aikataulun mukaisesti. Toimintatutkimusmenetelmä mahdollistaa jatkuvan muutoksen palvelua pilotoidessa ja testatessa. **Neljännessä (4) vaiheessa** eli pilotointijakson päättymisvaiheessa kohderyhmä vastaa asiakastytyväisyyskyselyyn jota käytetään mittarina palvelun toimivuudesta jatkossa. Koko tutkimusprosessin ajan tutkija kirjoittaa reflektovaa päiväkirjaa ja kirjaa muistiin palvelussa esiintyviä ilmiöitä ja ajatuksia. **Viidennessä (5) vaiheessa** koko tutkimusaineisto analysoidaan kvalitatiivisen sisällönanalyysimenetelmien avulla. **Kuudennessa (6) vaiheessa** tutkimus raportoidaan Master's Thesis:n (opinnäytetyön) muodossa ja julkaistaan Laurea Ammattikorkeakoulun kautta.

Tutkimuksen toteuttaja: Sara Asteljoki, Sh, on Laurean Master's opiskelija joka on työskennellyt erikoisterveydenhuollossa ja yksityisellä terveydenhuollon sektorilla seitsemän vuoden ajan.

Ohjaajat: Yliopettaja Paula Lehto, Yliopettaja Maria Suokannas, Yliopettaja Vesa Taatila, Laurea Ammattikorkeakoulu, Otaniemi Espoo.

Yhteystiedot: sara.asteljoki@laurea.fi

APPENDIX 3 Hei Kaikille :)

Ja iso kiitos tässä vaiheessa mukaan tulemisesta ! Tutkimus toteutetaan telekonferenssiteknologiaa eli kuvapuheluyhteyttä hyödyntäen joten sitä varten tarvitsisin teiltä kaikilta muutaman tietokoneita koskevan tiedon:

- 1) Minkälainen nettiyhteys sinulla on käytettävissä (ADSL/ SDS, eli mega määrä/ nopeus ja vastaanottavuus) ?
- 2) Minkälainen tietokone sinulla on käytettävissä (PC) ?
- 3) Onko tietokoneessasi web kamera vai onko sinulla erillinen web kamera ?
- 4) Oletko käyttänyt tietokoneesi mikrofontia ja/vai onko sinulla erillinen kuuloke/ mikrofonti yhdistelmä (head set) ?

Nämä tiedot siksi, että pystymme valitsemaan toimivimman järjestelmän ilman suuria teknologisia ongelmia.

Minulla on käytössä Acerin PC (kannettava) ja Elisan makkula (toiseksi nopein yhteys). Läppärissäni on kamera ja mikrofonti (useimmissa kannettavissa tietokoneissa on sisäänistutettu mikrofonti).

Tutkimus on siis tarkoitus toteuttaa täysin sähköisesti ja teknologia toimii vain mahdollistajana kanssakäymiselle, siksi nämä tiedot ovat tärkeitä.

Seuraavassa sähköpostissa kerron koko tutkimuksen kulun erillisessä tiedostossa.

APPENDIX 4 Hyvä tutkimukseen osallistuja:

Tutkijana on Sara Asteljoki, Sairaanhoidaja, Master Degree of Health Promotion, Family Care & Leadership tutkinnon opiskelija (YAMK) ja idean innovaattori Laurea Ammattikorkeakoulusta. Tämä tutkimus on opintoihin liittyvä opinnäytetyö ja tutkinnon suorituskieli on englanti, täten tutkimusraportti on myös englanninkielinen.

Tutkimuksen tausta: Tutkimus on osa uuden ePalvelun luomisprosessia. Kartoitamme kohderyhmän arvopohjaa jolle uudenlainen ePalvelu voisi perustua. Laurea Ammattikorkeakoulussa on kehitetty HyvinvointiTV- konsepti eli vuorovaikutteinen televisioyhteys johon tämä palvelukonsepti perustuu.

Tutkimus kysymykset joihin tutkimuksessa pyritään vastaamaan ovat:

1. Minkälaisia elämänarvoja kohderyhmällä on?
2. Minkälaiselle arvopohjalle ePalvelun toiminnan tulisi perustua kohderyhmälle?

Tutkimusmenetelmät: Kyseessä on toimintatutkimus jossa käytetään etnografisen ja design tutkimuksen menetelmiä eli tarinankerrontaa ja ideointia kuvayhteyden välityksellä ja sähköpostitse.

Tutkimuksen kulku vaiheittain tutkimukseen osallistuvalla:

Esivaihe: tietokoneiden ominaisuudet ja internetyhteyksien nopeudet (sähköpostitse 8.10.2010)

- lähetäthän vahvistuksen tutkimukseen osallistumisesta sähköpostitse mahdollisimman pian?

1. Vaihe: Kirjoita tarina unen muodossa arkipäiväisestä elämästäsi (1-5 sivua).

- Kirjoittaessasi unen muodossa voit käyttää mielikuvitustasi siitä minkälaista myös toivoisit arkesi olevan.

Tarinan voit lähettää sähköpostiosoitteeseen astelcare@gmail.com 15.10.2010 mennessä.

2. Vaihe: internetin kautta tapahtuva virtuaalinen kanssakäyminen eli kuvapuheluyhteyttä hyödyntäen. Teknologiasta lähetetään erillinen ohjeistus ja **vaiheen 2** aikataulu suunnitellaan yhdessä teidän kanssanne 18.10.2010 mennessä. **2. Vaihe** aloitetaan aikaisintaan 18.10 jolloin vaiheen 1. sisällönanalyysin tulokset on käyty läpi tutkijan taholla.

3. Vaihe: Teidän kanssanne suunnitellaan alustava konsepti palvelusisällöstä ensimmäisen tapaamisen aikana, kun teknologia ja internet sovellus ovat tulleet tutuksi. Vaihe 3 jatkuu n. 2-3 vko:ta.

4. Vaihe: Tutkimukseen osallistuvien loppuhaastattelu palveluympäristössä ja sähköpostitse (valmis kysely).

Eettisyys: osallistuminen tutkimukseen on vapaaehtoista ja voit halutessasi keskeyttää tutkimukseen osallistumisen sähköpostitse. Tutkimus toteutetaan kuvapuheluyhteyttä hyödyntäen internetin välityksellä, niin, että useampi jäsen voi olla samaan aikaan yhteydessä keskenään. Kuvapuhelukeskusteluja ei nauhoiteta tai tallenneta. Tutkija tekee muistiinpanoja ja havaintoja kanssakäymisestä vain tutkimustarkoituksiin. Kyseessä on vain yksi osa ePalvelun luomisprosessia ja tutkija ei ole hoitovastuussa tutkimukseen osallistuvista henkilöistä. Tutkimus ei velvoita ketään kertomaan terveydentilastaan.

Tutkimus päättyy vaiheen 4 jälkeen, mutta palvelun mahdollinen jatkuminen ja sen sisällön tuottamisen jatkumo arvioidaan tutkimustulosten mukaisesti jo vaiheessa 3. Tutkimus on julkinen dokumentti ja tallennetaan Laurean tietokantaan. Teille ilmoitetaan tutkimuksessa saadut tulokset henkilökohtaisesti.

Ohjaavana taustaorganisaationa toimii Laurea Ammattikorkeakoulu, Otaniemi/ Espoon yksikkö.

Ohjaajina toimivat:

Yliopettaja Paula Lehto, Yliopettaja Maria Suokannas, Yliopettaja Vesa Taatila

Yhteydenotot ensisijaisesti osoitteeseen astelcare@gmail.com

Kohteliaimmin ja tarinoita odotellessa!

Sara Asteljoki

APPENDIX 5 Data Analysis grouping by data source

Results from short stories

<p>Friends Spouse Family Colleagues Child Boyfriend Mother Social interaction Conversations Children Support Patient organizations Pet, dog Mothers love New challenges for child Duties for family Steady relationship Boyfriends commitment Company Belonging</p>	<p>Themes linked to Social relationships and support</p>
<p>Joy Enjoyment of family Pleasure Kindness Love Joy of life Richness Peace Happiness Luck News Satisfaction Cleanliness Support Consideration Being Hope of spontaneousness Relativity towards own life situation Choices Memories Faith Irony Scents Humor Boredom Responsibility Atmosphere Smells Urge Duties Unacceptable behavior Motivation Sensations</p>	<p>Themes linked to Emotions</p>

<p>Sorrow Gratefulness Faith Belief (religion) Independence Loneliness Coping Hardships Anxiety Hopes Exhaustion Dreams Strength Well being (physical & mental) Contentment Worries Parenting, concern over child Fear Courage Need Belonging Must Reality Relaxing Expectations Pressure Secrecy Shame View towards life Adjustment Wondering Unpleasant Avoidance Motivation Interests Imagination Learning Conditionality Goal orientation Moods</p>	
<p>Depression Illness Dentist Dialysis treatments Other actions related to dialysis sick leave Restrictions Child's illness Nutritional disturbances Path with the disease Coping with the machine Health Eyesight Wellbeing Teeth Technology how treatments are carried through Physical well being after treatments Complications</p>	<p>Themes linked to Illness and Health</p>

<p>Drinks Food Appetite Restrictions Irony towards food Pleasure of eating Social action Shopping difficulties Boredom of restrictions Bate Hunt Cooking Eating Alcohol Difficulty of cooking/ mess Tasty</p>	<p>Themes linked to Food</p>
<p>Summer 4 seasons Morning Morning chores Day off Civil War Evening Time consumption Age wake up waiting darkness Daily life History Daily events Spontaneous Planning Routines Change of plans due to difficulties of time Finishing working day Memories News What certain age groups are expected to do Attempt Slowness Old car preparations for winter life experiences</p>	<p>Themes linked to Time</p>
<p>Change of appearance Swelling Unrecognizable Self- image Body image Expectations towards appearance Masculinity (in females) Change of self image due to illness Sexual intimacy (change)</p>	<p>Themes linked to Self Image</p>
<p>Sleep Tiredness Chemical sleep Quality of sleep</p>	<p>Themes linked to Rest</p>

Well being	
Home Weather Atmosphere Temperature Events in the environment Driving Traffic Features of the car Driving skills Starting the engine Nature	Themes linked to Environment
Music Art Colors Gardening Dancing Events TV Pet Sports Nature Books Recorded books Rowing Swimming Listening Relaxing Reading Music Traveling Handcrafts Radio	Themes linked to leisure e.g. Entertainment & Hobbies
Army Work Responsibilities Division of work Preparing for action	Themes linked to Duties & Responsibilities

Results of individual interviews

Consumption of time Time Possibility to do treatments at home History Daily life "Killing time" Routines Useful time Must	Themes linked to Time
Family roles Responsibilities Support and help from next of kin Marriage Commitment Friends Safety Belonging Love	Themes linked to social relationships
Internet - e-mails - bank services - discussion boards TV radio Movies	Themes linked to actions during treatments
Important, Huge issue Personal issue Genuine Individualism "Palace of oneself" Spontaneity Free to decide Loss of freedom Limited Planning, restricted Ability to move freely	Themes linked to Freedom
Learning new things Expectations towards new things Learning languages	Themes linked to Learning
Tiredness, exhaustion Treatments (dialysis) Feeling better due to treatments Motivation towards treatments Satisfaction towards Health Care System Support Help Controls Rehabilitation Limited resources Positive experiences	Themes linked to Illness
Eye sight Touching, feeling	Themes linked to Senses
Serenity Richness of things in life Inherited items	Other

<p>Art Culture Skills; baking Admiring; a fan Honesty, Togetherness Gardening Sports</p>	
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Group interview

Grouping of contexts and interpretations of meanings in the data analysis

Context of conversation	Meanings of the context
Work	Most important from the perspective of time consumption (respondent 1)
Illness	Most important from the perspective of time consumption (respondent 3)
Family	Most important from the perspective of time consumption (respondent 2)
Illness	Types of dialysis treatments. Participant 1: Home hemodialysis, Participant 2. Home peritoneal dialysis, Participant 3. Hemodialysis at the hospital polyclinic
Experiences of Chronic Kidney Disease	Respondents discussed individual situations, asked specifying questions concerning treatments and techniques. All respondents had experience of dialysis but were unknown to each other, however mutual understanding was present.
Independence	Home dialysis, time consumptions, Fistel
Dialysis treatments	Technology and implementation, time, route, location
Background questions of experiences	Positive experiences, negative experiences
Illness	Knowledge of physical condition, insertion of needles independently rather than health care staff
Information, knowledge	Learning, Support
Sharing difficult experiences	Illness, parenting, disappointments of hopes concerning transplantations, pregnancies
Family	Spouse, children, relatives, friends, siblings, motherhood, parenting
Transplantation e.g. being on the list	2 of the respondents are on the list, one of the respondents has had two transplantations, however, care has continued with hemodialysis and the respondent is not on the list due to personal preference (Numbering of the respondents is not used in this section)
Career, life path	Time, Age
Nature	Warer, snow, sports, gardening
Senses	Decreased eyesight
Internet	Profession, important factor, time consumption, services, "killing time" during treatments, possibilities, link to outside world, communication enabler, reading, shopping, banking services
Food	Tasty, emphasised role due to CKD, limitations
Freedom	of choice, society tends to limit due to illness, struggle over own freedom, freedom of speech, freedom of thought, possibilities, dream of acting freely
Internet and freedom	Possibilities, positive and negative sides, discussion forums, information, mass media, magazines, organizations (Musili), unawareness before internet, knowledge of different

	countries and health systems, gives perspective through information
Does freedom release time for daily life	Through banking services, also "steals" time, entertainment time online
Ideation of words	"Cosmic annoyance"

APPENDIX 6 Original quotations

a) Kotiudumme retkeltämme ja lounastamme. Keitto on muhinut pitkään ja maistuu herkulliselta syysretken jälkeen

b) Seuraavana ohjelmassa on ruokakaupassa käynti, joka on aina yhtä hankalaa. Joudun odottamaan äitiäni, joka auttaa kassien kannossa. Minulta se on kielletty, ellen halua metrin tyrää. Kaupassa haahuilemme tapamme mukaan useita toveja. Äiti laihduttaa ja minä en saa syödä fosforipitoisia tuotteita ja kihtikin rajoittaa ruokavaliota, joten ostosten tekeminen on hankalaa. Silmäilen suklaaosastoa, mutta se on erityisesti kiellettyjen listalla. Onneksi kasviksia saa sentään syödä.. Päädyimmekin tekemään kasvissosekeittoa. Olen aina ollut kulinaristi, joten hieman yksipuolinen ruokavalio tyslistyttää. Kassalla tuttu täti tuijottaa, mutta ei selvästikään tunnista. Suuret kortisonimäärät ovat turvottaneet kasvoni järkyttävän näköisiksi. Hymyilen vain, enkä halua kertoa, kuka olen. Kertominen vain vaatisi myös selitystä uudelle ulkomuodolle, enkä välittäisi siitä puhua.

c) Se olo mikä mulla oli noin vuosi ennen hoidon alkamista oli niinku niin väsynyt, että käytännössä nukku kun tuli töistä ja dialyysiyksiköstä, mä olin niin väsynyt, että käytin oikeestaan koko ajan siihen, että nukuin 2-3h, että pystyin normaalisti toimimaan. Sen jälkeen kun olin ollut pari kuukautta hoidossa niin olin selkeesti niin paljon paremmassa kunnossa, että mun on niin paljon vaikeempi kokea se aika nyt turhaksi sen takia, että se on mulla se suuri motiivikin, se, että jos mä lopettaisin hoidon, että kuinka surkeeseen kuntoon mä menisin.

d) Hoitojen aikana lukee sähköposteja, hoitaa netissä pankkiasioita ja kyllä se on sellasta ajan tappamiseen käytettävää aikaa. Tai sitten on semmosia, jos on aloittanut jotain telkkarista, niin kattelen sieltä niitä, siinä on hyvää aikaa niitä tehdä.

e) (spontaanisuus) on itselle tosi tärkeä juttu, eli on aina ollut itselle tärkeä juttu sellainen spontaani tekeminen ja yhtäkkinen päätöksenteko moniin asioihin. Se on aika rajoitettua nyt tietysti. Että näitten hoitojen kanssa vekslaaminen ni se vaatii aika monista asioista suunnitelmallisuutta, mutta kyllä se aika haittaa sitä semmosta tekemistä mitä itte haluais asioita tehdä.

f) Ystävämme piipahtavat kävelylenkillään. Heitä on mukava tavata. Juomme teetä ja rupattelemme. Pohdimme terveyttä ja sairautta. Iloja ja suruja. Puhumme lapsistamme. Heidän iloistaan ja suruistaan. Muistelemme kesää. Nautimme toistemme seurasta. Kiitämme jotain korkeampaa siitä, että hän on antanut ystävät ihmiselle. Nauramme tuota kiitosta, koska kukkaan meistä ei kuulu kirkkoon.

g) Kotiin päästessäni poikaystäväni soittaa ja kertoo, että pääsisi viikonloppuna armeijasta kotiin. Ilahdun, koska rakkaan tuki on aina ollut tärkeää. Armeija osui siinä mielessä

hankalaan kohtaan, koska olisin tarvinnut häntä kotona tukenani. Asumme yhdessä, mutta viikot olen äitini luona, koska tarvitsen apua monessa asiassa.

h) Poika, mies ja perhe. Perhe on hirveän tärkeä, hitsauduttu kolmikko yhteen. Jonkinlainen turvallisuus siinä on, ja tottumustakin. Niin, se on tärkeitä elämässä mitä minulla on tässä, eli olen yksikön jäsen.

i) Vaikka arki on rankkaa ja monesti voimat ovat vähissä, tunnen silti itseni onnelliseksi. Perheeni tukee niin henkisesti kuin fyysisesti ja minulla on vankka kaveripiiri.

i1) Katson itseäni peiliin ja käännän vaistomaisesti pääni. Se, mitä näen ei miellytä. Kasvot ovat turpeat ja olemus pöhöttynyt. Ihon on kortisonin takia revennyt kauttaaltaan ja karvankasvu on kammottavaa. Näytän väsyneeltä ja surulliselta. Meikilläkin saisin näyttämään itseni vain pelleltä. Ahdistaa.

j) Dialyysikatetrin laitton jälkeen hän (poikaystävä) piti itsestään selvyytenä, että seksielämämme jatkuu normaalina. Katetri oli kuitenkin liian iso asia, jotta olisin voinut tuntea itseni rennoksi. Seksiä on edelleen, mutta harvoin ja silloinkin se on pakkopullaa. Onneksi suhteemme on niin vakaalla pohjalla.

k) Ajattelen, että voiko tämän parempaa elämää elää. Ihana mies. Ollut vierellä jo kohta kaksikymmentä vuotta. Poika, kehitysvammainen ja autisti, mutta kaikkein rakkain. Mietin sitä mitä taisteluja olemme hänen kanssaan läpi käyneet. Ja sitä miten hyvin kaikki nyt on. Mietin sitä miten hänelle alkaa uusi elämä, kun oman kodin ovet aukeavat ja totutteleminen siihen alkaa. Ajattelen, että en pelkää tulevia haasteita. Kaikesta on selvitty. Ja kaikesta selvitään.

l) Päivän lopuksi totean olevani väsynyt, mutta seuraava jännitysmomentti seuraa siitä arvonnasta tuleeko uni sifrolilla vai ilman. Sifrolin kanssa nukkuminen on hiukan samankaltaista kuin Johnny Walkerin kanssa nukkuminen.

m) Herään aamulla virkeänä. Olen nukkunut kokonaisen yön heräämättä. Mieheni tuhisee tasaista untaan vierellä. En raaski häntä herättää.

n) En voisi elää kodissa jossa ei olisi värejä. Punaista, sinistä, violettiä. Ja vihreää. Kukat ovat minulle tärkeitä. Huomaan pölyö lehdissä ja haen rätin millä voin niitä pyyhkiä. Tuntuu, että ne aivan kehräisivät tyytyväisyydestä. Ne nostelevat kauniita lehtiään ja näyttävät entistä vihreämmiltä

o) Työmaan ovella totean taas, että kahdesta samanlaisesta avaimesta oikeaan lukkoon laittamisen mahdollisuus on n. 25% luokkaa. Onnistun kuitenkin pääsemään työhyoneeseeni ja vaihtamaan vaatteeni. Avaan tietokoneen ja työpuhelimien ja mutustelen samalla eilisiltaisia leipiä, jonka päälliset ovat levinneet muovipussin sisälle.

p) Katson televisiota tehdessäni dialyysihoitoa. Siitä on tullut uusi harrastukseni. Nyt sieltä tulee isännän ja koiran käyttökoulu, jota katson mielenkiinnolla ja yritän saada vinkkejä oman remmiräyhäni kasvatukseen. Jaksamiseni on ollut hoitojen ansioista parempi, joten kävimme turreni kanssa opettelemassa naksuttimen käyttöä.

q) Nousen ylös vuoteesta ja lähdän ”pussittamaan”. Valutan takkahuoneessa nesteitä edestakaisin ja kuuntelen Raimo Pollarin kokooma Iskelmäradiota. Lauleskelen vanhoja iskelmiä, ja tunnen herkullisen kahvin tuoksun nenässäni.

r) Meillä on autistinen poika, joka tarvitsee päivä struktuurin ja meistä jompi kumpi on aina hoitaja, eli hoitajan työtä.

s) Työ: elämäntehtävä, tapa yhteiseen vastuuseen

t) Ikääntynyt autoni on halukas käynnistymään, mutta ei käymään. Joudun kiusaamaan autovanhusta useaan otteeseen. Tuulettimenhihnan kiljunnan säästyksellä peruutan auton pois pihasta. Aamuliikenne on tavanomaista, tosin aina joukossa ajelee joku jonka olisi kannattanut nukkua pitempään tai jäädä kotiin.

u) AK 96. Ei, kysymys ei ole itäisen naapurin valmistamasta uudesta rynnäkkökiväärimallista. Kysymys on läntisen naapurin valmistamasta Gambro merkkisestä dialyysikoneesta. Tämä lähes kokoiseni ja painoiseni laite on perheemme 5. jäsen, lapsen, vaimon. Koiran ja itseni lisäksi. Suhde AK96:n on erittäin läheinen, etten sanoisi. Aika ajoin kiinteä. Sääli vain, että tämä kaveri ei pärjää ilman apuani, enkä minä ilman sen apua. Kun aika meidät toisistamme joskus erottaa, en jää kaipaamaan. Joka tapauksessa tänään taas olisi tarjolla taas 3h laatu-aikaa tuon sinivalkoisen verenimijän seurassa.

u2) Hoidoissa olen kulkenut jo monta vuotta, joten se on osa minun elämäni. Näön menettämisen vuoksi tarvitsen joka päiväisissä askareissa avustajaa. Alkuhankaluuksien jälkeen on ihanaa huomata, että joka päivä oppii omaksumaan jotain uutta.

u3) Spontaanius elämästä on poissa, tämän opettelu on ollut haasteellista, koska on ollut hyvinkin spontaani ihminen 16 vuotta sitten. Pojan sairaus on myös ollut elämänkoulua.

u4) Mitä täydellisellä vapaudella sitten tekisi, sitä en tiedä? Se on illuusiona olemassa, sitä voi haikailla.

u5) Vapaus on iso arvo, tärkeä, henkilökohtainen vapaus, omahetuisuuden ja aitouden ”omilla elämisen valtakunta.” Arvohierarkiassa kärjessä ja olen individualisti.

v) Käden taidot ovat omalla kohdalla tulleet tärkeiksi ja osaan arvostaa niitä tosi paljon. Käsillä joutuu itsekkin aika paljon tekemään, tunnustelemaan ja ottamaan kontaktia toisiin ihmisiin.