

# Design for Dignity

## How to make cancer patients feel worthy of receiving help from volunteers

Benedicte Blix

Department of Product Design  
Norwegian University of Science and Technology

### ABSTRACT

It can be very difficult to ask for help, and reasons for this are numerous, whereas not feeling worthy of receiving help is one of them. This paper is written in collaboration with The Norwegian Cancer Society (Kreftforeningen), who is currently developing a service aiming to offer cancer patients voluntary help with practical tasks at home. When helping those in need, we hold someone else's dignity in our hands. The paper focuses mainly on how to preserve cancer patients dignity when offering help. The topic has been investigated through a literature review, participation at a seminar: *Dignity - in theory and practice*, workshops, and a brief market research. The identified guidelines for offering help are as follows: *Show respect, openness and friendliness, ask what the patient needs help with and strive for continuity for the patient*. In addition, it is essential to show that one cares, although this is not included in the current policies considering elderly care.

**KEYWORDS:** Participatory design (PD), cancer patient, elderly, help, dignity, volunteers.

### 1 INTRODUCTION

Kreftforeningen is currently developing a service aiming to offer cancer patients voluntary help with practical tasks at home. Initial research made by Kreftforeningen implicated that convincing the cancer patients to accept help, is one of the main challenges. [1] It was hypothesized that the resistance of receiving help was linked to dignity, resulting in the problem formulation: "How to make cancer patients feel worthy of receiving help from volunteers". The consequences of not receiving help when suffering from cancer can sometimes be severe, for instance cases where relationships risk being destroyed or children take on too much responsibility at home. [1, 2] This paper is particularly important for the abovementioned project, in order to develop a service where patient needs are taken care of, but can also be used for other purposes where help is offered. It attempts to search for some universal truths considering human dignity in care, and recommends further research on areas where the results are unclear or ambiguous.

The topic is investigated in order to help people manage their illness and to raise awareness on how to offer a dignified care.

This is conducted through a literature review, examining dignity in elderly care. Findings were used as part of a basis to create two workshops including both former cancer patients and volunteers, in collaboration with the project manager Gunn-Berit Neergård. The author also attended a seminar; *Dignity in the elderly care*, in October 2015. Findings from three earlier workshops led by Neergård are also used in this study. In addition, a brief market research in a Facebook group for cancer patients with 1600 members was conducted. The results are then compared with the results from the study about dignity in the elderly care. Several of the methods used, showed that it was important to offer the right amount of help, meaning that it could be degrading to be offered more help than necessary. [3] [4] [5] Considering how to make cancer patients feel worthy of receiving help, it was discovered that most cancer patients already feel worthy of receiving help. There are however other reasons for not reaching out, such as lack of information, or reluctance to talk about their diagnosis. [1, 6]

## 1.1 What is dignity?

One definition of dignity, made by the German philosopher Immanuel Kant, stated that there were things that should not be discussed in terms of value, and that these things could be said to have dignity. In his view, human beings have "an intrinsic worth, i.e., dignity," which makes them valuable 'above all price.' [7] According to the now retired health teacher Solveig Angel Danielsen, dignity was first established in religious texts, such as the Bible. [8] For instance: "There is neither Jew nor Greek, there is neither slave nor free, there is no male and female, for you are all one in Christ Jesus." [9] However, dignity was a royal privilege for decades. In the English Bill of Rights of 1689, only royal dignity was recognized. [10] Further on, the term developed, and it was rephrased in the Universal Declaration on Human Rights; "All human beings are born free and equal in dignity and rights..." [11] This means that your dignity is independent of your actions, hence it is preserved whether you're good, bad, hurt someone else, or hurt yourself. The latter has unfortunately been disregarded many times within health care. An example of this was presented during the seminar, referring to cases where nurses sewing self-mutilators have commented: "you like this don't you?" [12]

In nursing homes, most elderly are well taken care of, but there are some exceptions. According to two professors in nursing, Dagfinn Nåden and Vibeke Lohne, violation of the elderly is a part of everyday life at Nordic nursing homes. A study of six Nordic nursing homes showed that the elderly were often violated in daily activities, for instance if they need help going to the toilet at night, but are instead left to themselves. They are no longer seen as persons in need of help, but more as a burden. Psychological humiliation can also occur, for instance when hearing-impaired residents are perceived to be demented. In cases like this, they are often spoken to as if they were children. [13]

Considering cancer, some types of cancer can be more stigmatizing than others. For instance, lung cancer patients often experience stigma, due to the strong association to smoking. [14]

It can also be difficult to share that one has cancer, partly due to avoidant friends and acquaintances, or in an attempt to avoid comments or glances from others indicating that they feel sorry for you. This causes many people to keep the disease hidden, if possible. [5] [15]

If we were to describe a life worth living, many of us would probably include laughter. [16] Laughter can improve health, brain-function and memory, according to new science. [17] However, there are no requirements of laughter for the elderly, reading the Norwegian guarantee of dignity: 'Verdighetsgarantien'. [18] According to the journalist Brita Blomquist, humor should be implemented in the Norwegian guarantee of dignity. [16]

## 2 METHODS

In this paper, dignity in the elderly care is compared to dignity for cancer patients receiving help from volunteers. The article consists of a literature review, where sources are articles, reports, blogposts and legal documents concerning dignity in the elderly care. In addition, the author attended a seminar; Dignity in the elderly care, in October 2015. The article is written parallel to a service design project in collaboration with Kreftforeningen, where the author has led two workshops including former cancer patients and volunteers, and contributed to a brief market research posted on Facebook.

### 2.1 Literature review

The literature review is an analysis of concepts where *the requirement of help, the elderly, volunteers, stigma and/or dignity* is included. However, when including 'volunteers' in the search of articles online, many articles focused on the volunteer rather than the patient. The search was therefore expanded to include help from others as well. The literature review is used to ensure thorough understanding of the topic, and for comparing existing theory with findings from the workshops and market research.

The elderly are to a certain extent stigmatized for instance when they are no longer seen as productive, but rather as an expense to the

society. Discrimination due to productivity is however only one out of many reasons for discrimination against the elderly. Examples of discrimination can be found in the workplace, where the elderly are overlooked during promotions, [19] or when they want to apply for a job, but it is only available for the younger generation. [20] When the elderly are so openly not valued, it becomes more difficult to ensure a dignified elderly care, according to nurse and doctor in nursing science Linda Rykkje. [21]

Elderly care in Norway is based on the guarantee of dignity (Verdighetsgarantien). [18] It aims to ensure that elderly care is organized in such a way that it contributes to a dignified, safe and meaningful old age. [18] The guarantee emphasizes, amongst other, continuity during treatment, where the patient is assured thorough follow-up from medical doctors and therapists. According to coordinator of dementia in Hamar, Anita Stenhaug, continuity and predictability are the essence of good elderly care. [22]

Facilitating for privacy is also an objective in the guarantee of dignity, where elderly living in a health facility are entitled to private rooms. It is desirable to counteract the following: "With increase in age, people face privacy loss due to a higher need for care and increased dependence on others." [23] The concept of privacy is however complex and multi-dimensional, meaning that it covers social, physical, psychological as well as informational issues. Privacy can be violated on many levels, for instance when the elderly have to speak with their nurse or physician to the hearing of others. [23] It can also be compromised through the lack of space: In the article about health-care built environments, patients took pictures representing their dislikes, and these often showed scenarios where their privacy was compromised. [24, p.268]

Rykkje points out, however, that there is something missing in the guarantee of dignity: "to show that one cares". [21, p.3] According to the Bible, showing that one cares, is vital when helping others: "If I give all I possess to

the poor (...), but do not have love, I gain nothing." [25] Within the treatment of dementia, showing empathy is also considered one of the key elements. [26] Through inspiration from Denmark and the Fredericia model, [27] which aims to help the elderly live at home longer by focusing on training and self-reliance, there has been an increased emphasis on providing the right amount of help. The concept of offering the right amount of help has its own term in Norwegian, which translated reads: "to work with ones hands on the back." The expression is well known within many types of assistance, such as rehabilitation and nursing care. [28] [29] The method requires patience, meaning that it can be easier to do everything for the patient, rather than encouraging to self-reliance by offering the right amount of help. [29] [30]

According to the reverend Sten Sørensen, it is important to feel useful in everyday life and in society, in order to preserve ones dignity. [31] In recent years, there has been an increasing focus on making the elderly feel useful and viewing them as a resource, thereby encouraging them to become more self-reliant. [32] [3]

A weakness of this literature search is that the articles including volunteers, mainly focused on the benefits and experiences of the volunteer, rather than of the ones receiving help. Further, the aspect of receiving voluntary help versus professional help could not be covered adequately in this study.

### **2.1.1 Seminar: Dignity - in theory and practice**

October 22nd 2015, the author attended a seminar: Dignity - in theory and practice. [33] The seminar was held by the foundation for enjoyment of life for the elderly, (Livsglede for Eldre) in collaboration with Trondhjems hospital, Nidaros Cathedral and Vår Frues Church In Trondheim. The seminar consisted of nine lecturers, whereas the lectures by Øyvind Sørensen, Per Fugelli and Brita Blomquist are mostly referred to in this paper. Most of the lecturers had experience within healthcare. The seminar was helpful to acquire general knowledge about dignity, and focused on some

aspects concerning dignity that had not yet been prominent in the literature search.

During the lecture held by hospital chaplain Øyvind Sørensen about values and dignity, he claimed that we have a tendency to regard others on the basis of how productive they are. He stated that: "Every grown man should always carry a picture of himself as an infant, to remind himself that he has not always been productive." The message was that we must rather focus on the inherent, inviolable dignity, which is independent of age, living situation, or, for instance, if you've hurt someone. The only requirement for dignity is that one is human. The lecture was also about offering the right amount of help. One of his patients recently stated: "If you help me more than I need, I'm reflected as a person who needs more help than I do." He therefore concluded that there must be balance between respect, care and responsibility (see figure 1). [4]

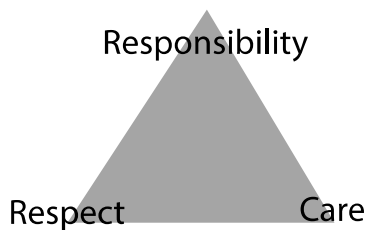


Figure 1: Balance triangle

The Norwegian professor and medical doctor, Per Fugelli held a lecture about how ones dignity is tested while growing older. He emphasized the importance of showing empathy, in this case from medical doctors. When he got his diagnosis of cancer, which was the better out of two severe cancer diagnoses, the doctor said: "This makes me glad", while holding his arm around him. It took him 1,4 seconds to say it, and the sentence consisted of only four words. Not a demanding gesture, but a very important one, according to Fugelli.

He also stressed that it is, to some extent, up to us to fulfill our own dignity warranty, due to our free will. Sometimes, diseases can unfortunately not be cured, and one can either look for a better version of oneself, or accept the situation as it is. [34] However, when

helping those in need, we hold someone else's dignity in our hands. [8]

In order to offer help that it is easier to receive, the ones offering help should, amongst other, try to meet the patient at common ground. To describe the concept, he used an example about a medical doctor in Africa who built his clinique out of mud and cow dung, which was the same material that the villagers used to build their houses. [34]

The journalist and program host Brita Blomquist held a lecture called: "Think new about growing old", where she questioned the current Norwegian guarantee of dignity. [18] She believes that the guarantee should include more about the right to have positive experiences when growing older, such as a good laugh. She argued that a description of a life worth living, most likely would include laughter. [16]

In contrast to the literature review, the seminar consisted of a selection of important topics, often chosen by professionals. In light of this, some of the topics were investigated further in both the literature review, and the workshops.

## 2.2 Participatory design

There are several concepts for human-centered design, whereas participatory design (PD) is one of them. To describe PD: "...one attempts to give future users of a system a role in its design, evaluation and implementation". [35] It is a process of mutual learning; hence it is not only a question of users participating in design, but also a question of designers participating in use, where the designer will try to share practice with users. [36] PD can also be viewed as a concept included in all the other known HCD methods (see figure 2). [35]

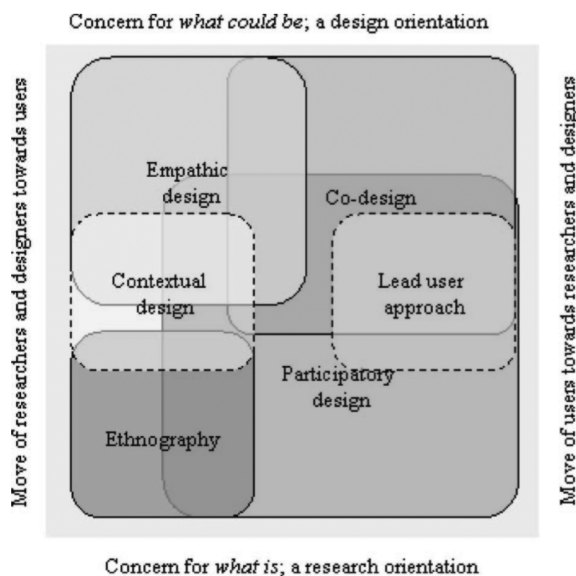


Figure 2: Different Human-Centered Design approaches.

In Scandinavia, PD has its roots in the trade union projects from the 1970's, aiming to improve the working conditions for employees, as new technology emerged and replaced their usual tasks. It was important to preserve democratic values at the workplace, meaning that the user's opinions of the new automatics should be heard. During the research and design process, PD was regarded a necessity in order to facilitate cooperation and communication between people with diverse backgrounds, according to Greenbourn. [37] From a political perspective, it was desirable that people were able to influence their workplace. [37]

Participatory design is also known as co-creation or co-design, and it has developed a strong tradition in Scandinavia. [38] Due to

more demanding consumers, and the emerge of new technologies, the user should no longer be seen as a passive receiver, but rather an active participant in the creation process. [39]

In a participatory conceptualization process, co-creation activities minimize possible misconceptions between user needs and the end product. [40] Amongst other fields, participatory design can be seen influencing healthcare, due to the completely different experiences of a designer and an actual user. [41] However, the evidence for the effectiveness of user involvement is both ambiguous and contradictory. [42] The user cannot only participate, but must also be able to influence the design. [43]

### 2.2.1 Workshops

Workshops are one of the core methods within participatory design, and it is an interactive group exercise. It can be a means of capturing more qualitative information, where behavior, justifications, motives and intentions are included. It also gives the participants the opportunity to challenge the agenda of the workshop, raising new issues, or asking questions back.

According to design strategist Penny Hagen, when designing for healthcare services, this type of design goes way beyond asking people what they want: "We need information about relationships, fears, dreams, places, thoughts, attitudes, activities, frustrations, priorities, motivations, and the like." Based on this, the questions are characterized by the emotional aspects, in addition to the practical ones.

When conducting workshops, it is however important to be aware of dominating personalities, or shy individuals who require encouragement. It should be regarded as an open-ended process, where the results can be ambiguous compared to results from, for instance, quantitative questionnaires. [44]

In this project, five workshops were conducted, whereas the two latter were led by the author. These included three volunteers and four former cancer patients, with the same

participants each time. Due to ethical considerations, only former cancer patients were included in the workshops. Personal questions were asked in the workshop, and in light of this, the first hour was exclusively used to get to know each other. Eight questions from the article "The Experimental Generation of Interpersonal Closeness" [45] was used, with an increasing level of intimacy. It was seen as important to build a trustful relationship between cancer patients and volunteers.

After dinner, the group was divided in two, with former cancer patients working together, and volunteers working together, with one facilitator in each group. During the discussions, cancer patients answered with their own opinions, whilst the volunteers answered what they thought the cancer patients would think. The objective was to see whether or not the volunteers' assumptions concerning cancer patients dignity, distinguished itself from the cancer patient's point of view.

Some of the research questions asked in this paper were: When receiving practical help at home: what are the most important factors to maintain your dignity? Why is it difficult to ask for practical help during cancer treatment? It was important to understand the reasons why many cancer patients do not want to receive practical help, in order to offer a service that it is easier to accept.

When discussing why it is difficult to ask for help, a lot of different proposals were suggested, thus almost none disagreed that it was difficult to ask for help. [5] However, there were some disagreements. For instance, when answering what the volunteers were not supposed to help with, one of the participants said firmly: "Don't come into my house!" whilst another one said: "The volunteers can come home to me and help me with anything, I'm not going to stop them!" [1]

In order to maintain the patient's dignity, the volunteers suggested that they could offer to help with different tasks. This was however not well received by the patient. They wanted to

be in charge, and would rather be asked what they needed help with. It was also very important to be treated with respect, openness and friendliness. All of the chores inside the house were seen as a challenge, due to the closeness of the volunteer. It was important to experience continuity, which means that each patient has few volunteers to relate to. More of the results from the workshops can be found in the next section.

A weakness with this approach is that the participants only represented a small selection of former cancer patients, all in the same age group, and may also represent the most resourceful former cancer patients. [1] In addition, when reading the results from the five workshops, there appears to be certain similarities within each workshop, indicating that the participants influence each other. However, when using workshops as a method, the participants are able to explain their views, ask questions back, and thereby reveal important aspects. Based on this, the use of workshops will probably result in a better fit between the users' need and the service. [46]

### **2.2.2 Market research**

A brief qualitative market research has been conducted in several Facebook groups for cancer patients, with feedback from eight women in total. Due to the broad resistance of receiving and offering help with chores discovered during some of the workshops, the questions were as follows: "Except chores, what tasks would you want help with during cancer treatment, if such a service existed?" and "Is there a high threshold to ask for help in a vulnerable situation, and if that case, how could this be lowered?"

The fact that chores were not offered at this stage met much resistance, and proved to be the most essential practical task to receive help with: "... Imagine if someone had rather offered to buy food or clean floors? This would enable more time for us as a family, time to create memories."

In cases considering families with children, the desire for continuity was mentioned: "I counted eight different people offering to babysit. We wanted maximum security and stability for our children, so we decided to use a minimum of babysitters during my sick period."

Several of the participants agreed that the threshold to ask for help was high, suggesting that the offer should be part of a package deal that you can simply accept, or that one could receive some information about the offer from for example an oncology nurse at the hospital. In order to lower the threshold, it should also be possible to write a message to Kreftforeningen, in addition to the current telephone service. The latter was substantiated by the fact that one might feel fragile during treatment, and thereby unwilling to disclose oneself. [6]

A weakness with this particular approach is that everyone's answers were visible within the group, which may affect the following answers. Although the answers were anonymized when the results were gathered, the participants were not anonymous to the others within the same Facebook group. One of the strengths of this method associated with the project was the ability to target current cancer patients in addition to former cancer patients. The market research contributed to change the focus back to including chores in the service. However, the qualitative data gathered can differ a lot, making them inexpedient to transfer into numbers and statistics. The answers must therefore rather be seen as tendencies. [47]

### **3 RESULTS**

The main findings from both the literature study and the workshops were that, in order to preserve a patient's dignity, three elements were emphasized: offering the right amount of help, striving for continuity, and most importantly, be kind. In addition, privacy was considered important, but the results from the workshops were very contradictory at this area. [24] [1]

#### **3.1 How to preserve cancer patient's dignity?**

According to the participants from the workshops, it is important to ask what they need help with, instead of assuming. Cancer patients often already feels that they should be able to manage everything themselves, [5] and it is important to counteract these feelings of inferiority. [4] They wanted to set the framework considering how help should be offered. [5] This was also important while taking care of the elderly, referring to examples such as the previously mentioned Fredericia model. [27]

It was considered desirable to receive help from the same volunteers each time. According to some of the workshop participants, continuity was important in order to avoid having to explain the situation over and over again: "If you have colostomy, you don't want to explain it over and over again to new volunteers." [5] Striving for continuity was emphasized in both the guarantee of dignity, [18] and during the workshops. In cases where the cancer patient had children mentioned in the market research, continuity was important in order to provide safety for the children as well. [48] Norwegian politicians support the demand for continuous help, offering severely ill cancer patients one contact doctor at the hospital.

For the volunteers however, it was important that they had the opportunity to change which cancer patient they would help, if the chemistry were not right. [5] When asking cancer patients who they wanted help from, most of them answered: "Someone whom they had a good connection with". This indicates a common goal for cancer patients and volunteers, regarding chemistry. [1]

There was a general agreement that the ones offering help should be respectful, open and kind. [5, 34]

Regarding privacy however, the results were quite ambiguous. According to the literature study, personal space was an important factor in preserving peoples dignity during

hospitalization, whereas privacy can help the patient maintain a sense of independence. [24, p.272] Results from the workshops showed that privacy was important to many of the cancer patients, although there were a few exceptions: "The volunteers can come home to me and help me with everything, I'm not going to stop them!" [1]

### 3.2 Asking for help

When researching the reasons why it can be difficult to ask for help, it was discovered that the difficulties are not exclusively linked to dignity. According to former cancer patient Karianne Bakken: "There can also be a high threshold there due to the difficulties of talking about the diagnosis, especially if you're emotionally on the edge." [6] In addition, it can be very difficult to acknowledge that you're not able to do all the things you usually manage. When asking for help, this compromises the desire to continue as usual, and highlights the lack of ability to carry out everyday tasks. At the workshop, one of the former cancer patients' describes the issue as follows: "You don't want to appear as more vulnerable than necessary."

It was however seen as more difficult to ask for help when the disease was not as acute; hence the signs of the disease were not as visible. Fewer people offered to help, and it was difficult reaching out. [5] Another reason why cancer patients did not ask for help was simply that they did not know the offers existed. [1] In other words, the patient can feel worthy of receiving help, but have other issues or obstacles stopping them from reaching out.

There are usually some differences between men and women, when asking for help. In Norway, men are statistically less likely than women, to see a doctor if they feel sick. [49] This tendency is also seen in former services offered by Kreftforeningen, such as "Workout buddy": a project where volunteers worked out with cancer patients. Here, a total of seventeen participants consisted of only four men, although the service itself was aimed equally at men and women. [1]

When discussing issues connected to receiving help from volunteers, there was a broad agreement that one might feel a debt of gratitude towards the volunteer. This was considered a stressful and unpleasant consequence of accepting unpaid help. [1] Another issue presented was the lack of equality between the volunteer and the patient: "The cancer patients are often bedridden and experience not to be presentable in the face of healthy people." [1]

There were some significant differences in the results between the workshops, and according to the first workshop, chores and taking care of kids were considered most appealing. [1] (See figure 3)

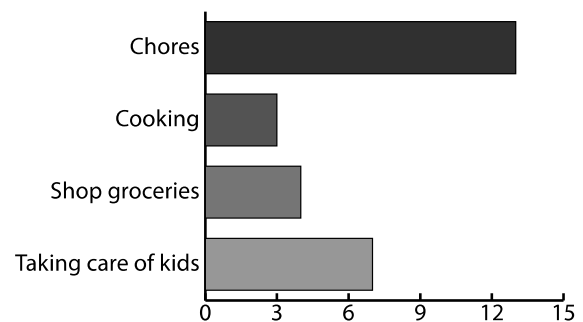


Figure 3: Preferable practical tasks.

Some of the workshops indicated that volunteers should not help with chores, and as a consequence of this, the latter was not portrayed as part of the service in the market research. However, several of the respondents commented: "Why not chores?" followed by a justification that this was something they needed help with. One woman replied: "Chores took most of my energy during treatment. Energy I would rather use with my closest family and friends." [48]

It has been pointed out through needs assessments that unspecified help, such as: "Let me know if there is anything I can help you with." is very difficult to accept. Offers like: "I'll make you dinner this week. Is Tuesday OK?" are often preferable, because one does not need to suggest tasks. [1] On the other hand, cancer patients claimed that they should be the ones setting the framework, when receiving help from volunteers. [1]



### **3.3 Consequences of not receiving help**

Results from the needs assessments conducted by Kreftforeningen, showed that it could be a great burden for the relatives or partner, when cancer patients were not willing to receive help from outside. [1] This could also affect the personal relationship between the cancer patient and their partner. The romantic relationship often changes into a relationship consisting of a cancer patient and a caretaker, making it very difficult to retrieve the initial roles. [5] The desire to help the cancer patient, often sacrifices the personal relationship. [5] This has led to several divorces and break-ups, claimed to be a direct consequence of the disease. [1] [5] However, one of the former cancer patients claimed that he and his partner would have broken up earlier, if it were not for his disease. [5]

Another aspect of not receiving help mentioned was that when the cancer patients finally realized that they needed help, they were often too exhausted to ask for it. [1]

## **4 DISCUSSION**

This paper attempts to answer the issue: How to make cancer patients feel worthy of receiving help from volunteers? However, as mentioned in the previous section, most cancer patients already feel worthy of receiving help. Based on this, this paper focuses more on how to maintain cancer patient's dignity, rather than how to change feelings of unworthiness into worthiness.

### **4.1 Cancer patients versus the elderly**

Although most cancer patients consist of the elderly, cancer can affect all age groups. [50] One of the most important factors in order to preserve both cancer patients' and the elderly's dignities found in this study was to offer the right amount of help. The term: "to work with ones hands on the back" was mentioned several times, and it was emphasized during the workshops. It can however be argued that this depends on the patients' disease or condition. For instance, there are certain differences between an elderly who needs rehabilitation, and a cancer patient who needs to rest. If rest is important,

the focus should probably not be on training and self-reliance, as it is in the Ferdericia-model. Although the premise for receiving help may vary, the method for preserving dignity can resemble. Due to the unambiguous results found in this paper, it is recommended that the project focus on offering the right amount of help.

The elderly were to some extent stigmatized and seen as a burden, partly due to lower productivity. When suffering from cancer, it was mentioned that it could be very difficult to acknowledge that you're not able to do all the things you usually manage. According to Sørensen [4], we have a tendency to regard others on the basis of how productive they are, meaning that the topic is relevant in all parts of our society. For instance, there exists a syndrom partly based on the urge to be productive at all times: the good girl syndrome (Flink-Pike-Syndrom, FPS). [51] The author perceives this as a problem that extends far beyond what this paper covers, hence further investigation is recommended.

### **4.2 Receiving help from volunteers**

The disadvantages of receiving help from volunteers referred to in this study, was the debt of gratitude towards the volunteer, and the lack of equality between the volunteer and the patient. Since the patient no longer has the opportunity to do as usual, feelings of inferiority can occur. The patient does not want to appear as more vulnerable than necessary. These are important aspect to consider in the development of the service, hence further research is recommended.

Reading the results from the workshops, there were major differences regarding how much privacy the different patients needed. The answers ranged from statements like "Don't come into my house!" to: "The volunteers can come home to me and help me with anything, I'm not going to stop them!" [1] There was a great need for help with chores, which is not compatible with staying outside the patient's house. It was also pointed out that it could be very difficult to receive unspecified help. In light of this, it is recommended that the project

group chooses a specific target group, and offers some selected tasks. Further investigation on how to best get in touch with the patient is also recommended.

There were many similarities between the findings of the workshops and the literature study, indicating that there are some guidelines on how to offer help:

1. Show respect, openness and friendliness.
2. Ask what the patient needs help with.
3. Strive for continuity for the patient.

The latter requires that one try to find volunteers who get along well with the patient. Considering this project, it is recommended that these guidelines be used during the training of volunteers.

To show that one cares has proven to be very important when offering help, but as Rykkje points out, this is not included in the Norwegian guarantee of dignity. [21] The author considers this a deficiency in elderly care, and recommends that this be implemented in new regulations concerning elderly care.

#### 4.3 Participatory design

One of the main challenges the designer meets when designing for healthcare experienced in this study, are the differences between their own perceptions, and the perceptions of the former cancer patient. This can also be found in British research considering healthcare, stating that: "The main issue is a lack of background knowledge and the completely different experiences of a designer and an actual user." [41] The opinions of the cancer patient has often been surprising, hence the use of PD has provided valuable insight in this project.

The workshops were useful and interesting, and as a bonus, the participants claimed that it felt good to reflect on their own experiences. [5] So far the feedback has focused on how former cancer patients think they would experience the service, but it is important to test how the service actually works as well. [52] In light of this, it is recommended that PD be used for further development.

## 5 CONCLUSION

In this paper it is examined how to develop a service facilitating that cancer patients experience dignity when accepting help from volunteers. However, most cancer patients already feel worthy of receiving help, and the difficulties of receiving help from volunteers during cancer treatment are not exclusively connected to dignity. The aspects on how to preserve cancer patients dignity is therefore emphasized.

Through a literature review, a seminar and the use of PD, three guidelines on how to offer help to cancer patients are identified:

1. Show respect, openness and friendliness.
2. Ask what the patient needs help with.
3. Strive for continuity for the patient.

To show that one cares has also proven to be very important when offering help, even though it is not part of the Norwegian guarantee of dignity. In order to facilitate for dignity in the service development, all four aspects are recommended to focus on.

## REFERENCES

1. Volunteers, F.c.p.a., *Needs assesment, "Help with Practical Tasks", Former cancer patients and volunteers*, G.-B. Neergård, Editor. 2015.
2. Guðbergsson, S.B., *Foreldre med kreft – bekymringer relatert til familienes levekår*. 2002.
3. Kristiansand, H.i., *Veileder til ansatte, Mestring gir muligheter*, in *Kristiansand kommune*, K. kommune, Editor. 2015. p. 8.
4. Sørensen, Ø.T. *Values and dignity*. in *Verdighet i eldreomsorgen*. 2015. Trondheim.
5. patients, F.c., *Workshop*, B. Blix, Editor. 2015.
6. Bakken, K., *Interview with cancer patient*, B. Blix, Editor. 2015.
7. Rachels, J., *Kantian Theory: The Idea og Human Dignity*, in *The Elements of Moral Philosophy*. 1986. p. 114-117,122-123.
8. Danielsen, S.A. *Dignity in practice - into everyday life*. in *Verdighetsgarantien i eldreomsorgen*. 2015. Trondheim.
9. *The Bible, Genesis 3:28*.
10. Legislators, F.B., *English Bill Of Rights of 1689*. 1688.

11. *The Universal Declaration of Human Rights of 1948*, T. UN, Editor. 1948, The UN: Europe.
12. Dolonen, K.A. *Alle får tilbud om bedøvelse*. [Article] 2103 November 3rd [cited 2015 October 10th]; Available from: <https://sykepleien.no/2013/04/alle-far-tilbud-om-bedovelse>.
13. Nåden, D., *Uverdige forhold på norske sykehjem*. 2015: Forskning.no.
14. Chapple, A., S. Ziebland, and A. McPherson, *Stigma, shame, and blame experienced by patients with lung cancer: qualitative study*. *BMJ*, 2004. **328**(7454): p. 1470.
15. LiveStrong, *LiveStrong anti-stigma campaigns*, in *Livestrong*. 2011.
16. Blomquist, B. *Tenk nytt om å bli gammel*. in *Verdighet i eldreomsorgen*. 2015. Trondheim.
17. Brækhus, L.A. *Latter er bra for hjernen*. ABC Nyheter [Newsarticle] 2014 29.04.2014; Available from: <http://www.abcnyheter.no/nyheter/2014/04/29/198707/latter-er-bra-hjernen>.
18. 2, R.S., *Verdighetsgarantien: Forskrift for en verdig eldreomsorg*. 2010.
19. Commision, A.H.R., *Fact or fiction? Stereotypes of older Australians*. 2013.
20. diskrimineringsombudet, L.-o., *Diskriminering av eldre i stillingsannonse*. 2007.
21. Rykkje, L., *Sann verdighet bygger på nestekjærlighet*. Bergens Tidene, 2011.
22. Sandberg, E., *Arbeidslag med fokus på demens*. Aldring og helse, 2009.
23. Ngwane, M.E., *Perceptions and perspectives of privacy in institutionalized elderly care*, in *Human Ageing and Elderly Services*. 2011, Arcada.
24. Douglas, C.H. and M.R. Douglas, *Patient-centred improvements in health-care built environments: perspectives and design indicators*. *Health Expectations*, 2005. **8**(3): p. 264-276.
25. *The Bible, 1 Corinthians 13, 3*.
26. Almvik, A., *Verdighet og eldreomsorg*. NAPHA, 2011.
27. Anker, M., *Fra byrde til styrke*. Danske kommuner, 2011(22).
28. Mikkelborg, Å.B., *Hverdagsrehabilitering - lengst mulig i eget liv i eget hjem*. 2011, Bodø Kommune.
29. Wahlberg, A., *Hendene på ryggen*, in *Andrea blogger*. 2015.
30. Anonymous, *Assistent på sykehjem*. Kvinneguiden, 2009.
31. Sørensen, S., *Eldreomsorg og ja til livshjelp*. 2015: Dagen.
32. Kaasin, E., *Se på senioren som en ressurs*. Idébanken, 2015.
33. eldre, L.f. *Verdighetsgarantien i eldreomsorgen*. in *Verdighet - teori og praksis*. 2015. Trondheim.
34. Fugelli, P. *Dignity - tested when growing older*. in *Verdighet i eldreomsorgen*. 2015. Trondheim.
35. Steen, M., *Tensions in human-centered design*, *Codesign*. 2011. **7**:1: p. 45-60.
36. Löwgren, J.e.A., *Thoughtful Interaction Design: A Design Perspective on Information Technology*. 2004: MIT Press.
37. Greenbaum, J.a.K., M., *Design at work: cooperative design of computer systems*. 1991.
38. Sundblad, Y., *UTOPIA: Participatory Design from Scandinavia to the World*, in *History of Nordic Computing 3*, J. Impagliazzo, P. Lundin, and B. Wangler, Editors. 2011. p. 176-186.
39. Wikstrom, S., *Value creation by company-consumer interaction*. *Journal of marketing management*, 1996. **12**: p. 359-374.
40. Park, J.Y., *Design process excludes users: the co-creation activities between user and designer*. 2012.
41. Glushko, A., *Participatory Design in Healthcare: Patients and doctors can bridge critical information gaps*, in *UX Magazine*. 2013.
42. Hirschheim, R.A., *Assessing participative systems design: some conclusions from an exploratory study*, *Information & Management*,. 1983. **6**: p. 317-327.
43. Demodaran, L., *User involvement in the systems design process - a practical guide for users*. 1996. **15**: p. 363-377.
44. *Workshops*. [cited 2015 6th of November]; Available from: <https://www.ucl.ac.uk/public-engagement/documents/evaluationtoolkit/evaluationmethods/Workshops.pdf>.
45. Al, A.e., *The Experimental Generation of Interpersonal Closeness: A Procedure and Some Preliminary Findings*. Vol. 23. 1997. 363-377.
46. Steen, M., *Benefits of Co-design in Service Design Projects*. *International Journal of Design*, 2011. **5**(2): p. 53-60.
47. Mogstad, L.M.T. *Kvantitative og kvalitative metoder*. [cited 2016 13th of January];

Available from:

<http://ndla.no/nb/node/93376>.

48. patients, C., *Market research*, K. Bakken, Editor.
49. Lilleaas, U.-B., *Kvinner har lite å lære av det "sterke" kjønn om sykefravær*, in *Aftenposten*. 2014: Aftenposten.no.
50. Kreftregisteret, *Fakta om kreft (Facts about cancer)*. 2016.
51. *Spørsmål og svar om flink pike-syndrom*. 2015 05.02.2015 [cited 2016 22nd of January]; Available from: <http://helplink.no/flink-pike-syndrom/>.
52. Kelley, T.a.J.L., *The ten faces of innovation: IDEO's strategies for defeating the devil's advocate and driving creativity throughout your organization*. 2006.