How could children be integrated into the situation when visiting a close relative in palliative care?

MFA Thesis
Stina Wessman
Advisor: Hlin Helga Gudlaugsdottir

Experience Design Group
Konstfack 2011
Table of content

Abstract 4

Introduction 5

Chapter 1: While saying goodbye
The hospice/palliative care 8
The staff 9
The family 10
The patient 11
The room 11
The bed 13
The cover 14

Chapter 2: Spending time at the last days
Difficulties in the situation 16
Sharing - children visiting palliative care 16

Chapter 3: playing between generations
Playing between generations 19

Chapter 4: Stripes
En randig sorg 21
Target 5-10 years 22
Chapter 6: Methodology
Observations 25
Interviews 25
Workshops 25
Pre school children 26
Primary school children 30
Nurses Axlagården 32
Nurses and designers 34
Interview and testing game 36

Chapter 7: Result
Guidelines/Criterias 38
Object details 39
Activity 41
Construction 45

Chapter 8: Discussion 48

Chapter 9: Conclusion 51

Chapter 10: Recommendations 53

References & Bibliography 55
Abstract

A recent study made at Stockholm University by Mikael Rostila and Jan Saarela from Åbo University showed that children bereaved from a parent suffer from mental health issues and have a higher risk of dying untimely. The conclusion Mikael Rostila, researcher at CHESS - Centre for Health Equity Studies, makes of this study is that more needs to be done to support children in their grief (Rapport svt.se).

To exclude children from the situation when someone is sick disturbs their grieving process. They feel excluded, unimportant and this can have consequences (Dyregrov). This thesis has further explored in what way children could be supported in their grieving and integrated into the experience whilst visiting a relative in the context of palliative care. As this research has discovered that the most common place of activity patients and kindred perform while visiting is to sit around the bed, it will specifically focus on activities for close relatives in this context of a palliative care unit.

There are many boundaries and emotional constraints in the situation when someone close is being cared for at the end of their life. The situation has many complex aspects that need to be taken into account when designing an experience. The main focus has been on developing the Blanket Book project thoroughly through a participatory design and research-driven co-creation with children, nurses and various specialists to achieve an appropriate outcome.
It is sometime in the middle of December 2006, I don't remember the date and time but I remember the emotional situation like it was yesterday. We are in the hospital room where my mother is being cared for. It is white, sterile and impersonal but strangely calm. The situation is latent terrifying and I remember a lame feeling in my body. We are totally out of control. My mother is sick, very sick. She is herself but much more tired. We are lying beside each other in the hospital bed. It is a little bit tight but the mental and physical closeness feels comforting. There is a blue pot with flowers, some cards and a little polar teddy on the side table. I gave her that teddy. He sits perfectly in the hand and he accompanies with her every time she is in the hospital. She has been in and out of hospital continuously during the last couple of months and her condition has slowly gotten worse.

I clearly remember one time when my brother came to visit with my two nieces. They are 5 and 7 now and have always been very close to my mother. There was a blouse she used to wear for special occasions. It resembles a theater set and has a special pocket where she would hide small surprises for them (see fig. 1). A piece of chocolate or a little animal. This intuitive relationship is absent when my nieces enter the room and they are hiding behind my brother, not knowing how to behave or what leg to stand on. The situation is unfamiliar to them and it disturbs the close loving relationship they have to my mother. We try to support them and make them feel comfortable but when they leave it is without comfort and feels unsatisfying. There are for sure no secret pockets in this situation.

Fig. 1. The blouse with the special pocket.
Introduction

There is today nothing purposefully made that includes or encourages children and patients in the situation when a kindred is receiving palliative care. In the best case scenario there are play corners with teddies, games and books for children in the palliative care facility. Children can bring toys and games into the room but are often hanging out outside of the room. This thesis is working with how a calm shared play between visiting child and patient can be encouraged in the room during a visit. It is positioned around the main topics that are also the keywords of this thesis; Slow activities, calm play, together, grief, expected death, strengthen relationship between generations, producing conversations, conversation piece. The aim has been to include the child by creating meaningful interactions situated around the bed during a visit for the visiting child and patient. Interactions that are building upon an existing relationship between the child, patient and take their situation into consideration.

Through a participatory design approach and literature review, observations and interviews have been executed to understand the different actors in the situation. The nature of the topic can be hard and difficult to talk about and there are obvious ethical constraints in including the main actors in this research. The research has therefor been planned and worked around to get reliable information without being intrusive. No patients or family members where interviewed in the actual situation. Instead nurses and assistant nurses have been the the main source to get to know the situation in the Palliative Care Center from the patients point of view. Pre- and primary school children have been involved in the process in a playful manner as that age groups and are the target group for the situation. Meeting and discussing with them has been a playful collaboration discussing aspects of playing with someone old, what is important when you play and how they prefer to play. Death was not discussed during these collaborations. The idea of ‘BäddBoken’ sprung from a previous transdisciplinary course where a collaboration between Stockholms Sjukhem, Axlagården Hospice AB and Konstfack took place. It was at the time a rough concept that has been taken further and developed. The basic idea of ‘BäddBoken’ is that you can place it over the patient on the bed encouraging interaction and slow activities during a visit.
Chapter 1:
While saying goodbye
The hospice/palliative care unit

Palliative care takes place in a patient's home or in a palliative care unit. Palliative Care has an holistic approach to caring at the end of life. It is not anymore actively trying to fight a decease but aiming to make the best out of the time being. Both the psychological, physiological, sociological and spiritual aspects are looked at by a multidisciplinary team consisting of nurses, art therapists, volunteers and care givers. Everyday they are working on providing a safe and comfortable environment for their patients and families (Beck-Friis 2005: pp. 13-14). The staff has an open attitude and are always working towards what each individual needs and wants from their last days. It could be everything from getting a patient’s favorite pastry on a daily basis, playing music to involving pets during the stay.

A nurse explains how “There was one guest who’s last wish was to ride a horse. So we got a horse here to Axlagården and the guest got to ride. It was a very nice feeling for everyone”. Stockholms Sjukhem and Axlagården has been the two palliative care units involved in this thesis. Axlagården is a Palliative Care center in the North of Sweden and is the first purpose built center in Sweden in 1992. It is placed outside of Umeå in a calm peaceful area and most of the rooms have view to the forest or natural surroundings. The concept of the building is the butterfly which is implemented in the architectural structure of the building and in small details. The butterfly represents the freedom after death. The building is built as two wings and, from a birds-eyes view, has the shape of a butterfly. The beds have small engraved butterflies as decoration. Axlagården has 16 rooms, 8 in each wing. Axlagården is spacious and there are two big rooms where you can hang out with music instruments, board games and a aquarium. One dining area and a green area with a pond and trees. They have a porch facing the forest with a view to the fields.

Stockholms Sjukhem has their palliative care unit on one of the four floors in central Stockholm. They have about 30 rooms and ASIH which is palliative care at home. The view is different in different angles. Some directions has trees and buildings on some and the street. The sound is for obvious reasons more noisy due to its placement and on top of that construction sounds of what is being built outside. The structure of the building is two big circular common
areas and the rooms are placed around these. The common rooms function as eating area and has big round tables and seating groups.

It is common to initially get palliative care at home and when the condition gets worse to move to the palliative care unit. At Stockholms Sjukhem’s palliative care unit, 50 percent of their patients are in the facility and the other 50 percent are receiving care in their homes. Primarily the patients are cancer patients for the simple fact that cancer has a more predictable process and the last days and weeks are more foreseeable.

**The people/actors**

There are many different actors in the situation when a patient is in Palliative care. Except from kindred to the patient the care facility has many different staff working in a week and even during a day.

**The staff**

The nurse and assistant nurse have both central roles during the end of a persons life. They are giving basal palliative care and spending a lot of time with the patient. Basal means primary importance and palliative care is relieving. A nurse works 80% because of the intensity in their work. The rest of the time is meant to function as time to re charge where they can do what they want. They are present in almost everything involving the patient from giving medication, help to shower, eating and brushing teeth. To get in contact with a nurse or assistant nurse each patient has a bell around their wrist that they can ring when they need something. The nurses have phones on them and the sound of the bell also come off outside the room where the patient called. The nurses work in shifts; morning, evening and night.

Axlagården have a strong tradition of volunteering. Volunteers are people coming in and doing various types of work outside of the care tasks. It could be to vacuum clean or to facilitate a BINGO session on Fridays. One of the volunteers used to be a hairdresser and is now cutting patients hair if they wish. During the observations it becomes obvious that how much time and
how often the volunteers work depends a lot, some come in for a couple of hours once a week and some many time in a week.

The doctor comes in at certain times in the week to check up and prescribe medication. The role of the doctor is limited and they are not spending as much times with the patients as the nurses and assistant nurses.

The family

The kindred are considered everyone who is close to the caretaker. Erika Lindqvist explains in an online course about kindred in Palliative Care, are an important cornerstone in Hospice philosophy (Lindqvist 2009). A comfortable kindred mean good support and is looked upon as one in the team and treated respectfully and including.

There are visiting hours but these are very flexible and kindred can stay as they feel. For some kindred it is perfectly natural to be physically close and to some it is a huge amount of tension and the amount of time during a visit vary from patient to patient. At Axlagården they have a guest room that kindred traveling from other locations can stay in for as long as they like and they have tent beds that can be placed in the patients room. At Stockholms Sjukhem there is no guest room but tent beds are a common procedure. It is common that kindred have physical and psychological symptoms such as head ache, back pain, tiredness from the emotional tension and from sitting and guarding around the bed (ibid) (see fig. 2).

The kindred often have many questions and thoughts and the information channels are very important. Accordingly to Lindqvist the informations should flow both verbally, written and be returning (ibid). At both Axlagården and Stockholms Sjukhem they have stands with folders and books related to the situation. Some of them are general information about grief and some are about how the body changes before death.

![Fig. 2. Kindred sitting around the bed.](image)
Common feelings for kindred are powerlessness, insufficiency, anger, loneliness, guilt, fear. This can result in the kindred feeling weak, helpless and troublesome and this makes the situation even worse. Including and involving the kindred plus giving them small task can be a great comfort and give a feeling of being needed and significant instead of powerless in the situation.

The patient

The condition of the patient at the end of life vary a lot. Some might just spend a couple of days in the care unit before passing away and some might get very healthy from the relaxing and caring environment that they can go home and live for another year. Some patients walk around in the care unit and go to art therapy everyday and some stay in their rooms the entire time. The situation of dying is as subjective as living in many ways and everybody have different situations and relationships. One patient might have ten grandchildren and one might only have one child, some are all alone. All these aspects needs to be taken into consideration when designing for this complex situation.

The room

A patient receiving palliative care is often tired and spending a lot of their time in their room. A room at Axlagården is about 25 square meters, has a bathroom, a sofa or chair, bed and side table. The style at Axlagården is natural with white fabric and wood and this is what you see in the rooms also. The bed is made out of wood instead of the standard metal framed hospital beds (see fig. 3). The walls are naturally cream beige with some flower details. There are a couple of art pieces with various motifs. A boat or a forest painting for example. There are dvd players and television in every room but a nurse says it is often very quiet, the important activity is to sum up. Some patients decorate their room a lot and some don't at all. Some patients hang up their own curtains and bring pictures to hang on the wall. The philosophy at Axlagården is that the patient has the room in the same way as a in hotel when a guest book and have their room. They can do whatever they want with it. From the moment they get access to the room it turns into
“their room”. Accordingly to a study about bedside objects in Hospice environments executed in the UK in 2009. Patients bring an average of 5.7 objects to the hospice. The overall finding is that people try to create a home away from home feeling with various types of objects. The most common is food and objects for distraction such as books, news papers and magazines (Kellehear, Pugh, Atter 2009).

The rooms at Stockholms Sjukhem are about the same size as at Axlagården. They are bit more sterile and the colors are white a beige. There are bathrooms in every room, a side table, two arm chairs with a table, a bed made of wood with metal rods, a television and some art pieces (see fig. 4).

Fig. 3. A room at Axlagården.

Fig. 4. View straight ahead from a bed at Stockholms sjukhem.
The Bed

The bed is a central piece in the palliative care situation. Not is everything such as side tables and hanger shaped around it but also the main piece of furniture the patient spend the most of their time in. Naturally this is also where the main activity is taking place. No matter if that means watching television, talking to a nurse, talking on the phone or having visitors. From an interview with a brothers and a sister who lost their parent, they said that the most common activity they did while visiting was “to sit around the bed and talk about the everyday life”. This was confirmed by the staff. The bed is where the action is. The bed and the cover of this area becomes a shared surface while spending time around the bed. The beds can be changed with a remote control to change the position. The remote control is hanged on the rods.

The bed generally consists of madras, sheet, cover and pillows. “We should do a research project about pillows” says a nurse from Stockholms Sjukhem a several times it is that important in the situation both the tactility and shape.

The bed or place where a person is spending their last time and dying is called ‘death bed’ and accordingly to an online etymology source it appeared in the 12 century and has not been changed since. What has been changed more is where the deathbed is located. Before it was common and more natural for people to be cared for and to die in their home. It was closer to all of the family living there while now 20% are dying at home, 35% are dying in special care units such as geriatric care and palliative care units and 45% die in hospitals. The numbers vary a lot depending on location. Where the care units offer caring at home more people die in their homes. It is common that hospital are used when being cared for in their homes. Accordingly to a survey done by socialstyrelsen to people over 65 year about were they want to die 48% said they would prefer to die in a hospital. Not to be a burden for kindred (Socialstyrelsen 2005).
The Cover

The cover obviously becomes as a central part if you spend a lot of time in bed. There are many types of covers. Hand made, patch work, crouched etc. At Stockholms Sjukhem they are hospital like blankets checked in white and blue or red. At Axlagården some are fleece patterned with roses. Tactility is an important aspect accordingly to occupational therapists in their everyday work at Palliative care units.

According to a swedish online synonym dictionary one of the synonyms for the word cover ‘täcke’ are: spela under täcket samarbeta i hemlighet, vara i hemligt samförstånd (med). (synonymer.se ). The later ones vara i hemligt samförstånd med meaning ‘having a secret connection to’ is rather suitable connotation for the situation this thesis is focusing on; When close relatives are spending time together around the bed in a palliative care situation.
Chapter : 2

Spending time at the last days
Difficulties in the situation

There are many difficulties during the last days of life. When the body shuts down you might not be able to control yourself as you normally could. Confusion, nausea, tiredness are just some example of symptoms that could appear. It can be hard for the closest to see the person they love not remembering things or faces. As it can be hard and feel humiliating for the patient to be unable to do normal things in front of family members.

There are also many boundaries from the kindreds perspective in the situation when someone close is being cared for at the end of their life. You might not know what to say and the whole situation can be perceived as frightening for everyone especially from a child's perspective. Children are often conservative when it comes to change and they want things to be as they were; Furniture, toys and smell. They are sensitive to smell and want things around them that gives them comfort and is familiar (Lugdigsson 2005: pp. 119-128). The palliative care unit is very different from the comforting surroundings of the home on all aspects. The smell is different and a lot of new people are surrounding the patient.

Sharing - children visiting palliative care

Children visiting Palliative care are often drawing pictures to the patient, at home or in the facility. This goes especially at Axlagården where they have an art therapy corner.

A nurse explained during an informal interview about a situation where a woman with 6 children, all boys and many grandchildren, was in the care unit. A four year old grandchild didn’t want to go into the room. Instead she sat down in the art corner. Started to draw and then started to talk. She drew an ice cream and talked about her grandmother and then she was ready to go in and proudly helped to roll out the bed.

Children often communicate and work through their grief in a a symbolical way through drawing pictures, playing or writing poems (Ludvigsson 2005: pp. 119-128)).

Today there are play corners in the palliative care units. There are teddies, some dolls, board games and other traditional toys. In both the care units visited, these corners are placed in the common spaces and most often played with outside of the room. The toys are regular toys put into the context (see fig. 5 and 6).
Fig. 5. The play corner at Axlagården

Fig. 6. The two play corner at Stockholms Sjukhem.
Chapter 3:
playing & relationships between generations
Playing & Relationships between generations

Playing is accordingly to Stuart Brown, president of the National Institute for Play, as fundamental as dreaming and sleeping (New York Times 2008). As this thesis is working around how a child and patient can communicate and be with each other at the end of life, playing between generations becomes a natural part. As mentioned in previous chapter children work through their grief by playing and drawing. Therefore three workshop sessions were planned and facilitated to find out what preferences the children aged 5-10 have on play nowadays.

Beyblade and pet shop is the most popular with both the pre- and primary school children. But also traditional games such as UNO, ‘under hökens vingar kom’ and lego. When they were asked what is important when you play they all agreed that everybody must think it is good and fun game and that anybody can join.

Playing with someone who is older- what do you do?

Experts on play was asked the above question during two of the workshop sessions. Five children from Slätterängens Förskola were the first ones to take the task on. When they were asked the question they thought for a while before answering:

*Calm games, mama, papa, child, almost anything, barbie, puzzle, cosy, read a book with a dog called Börje, jump in the tents madrass. "You should be careful so you don't break your back, old people can be fragile" (Svante 5 years old).*

During the discussions with the children it becomes obvious that playing with someone who is older is often a little bit calmer than playing with a friend their own age. They do not put any negative values in it, the conditions are just a little bit different. They said that baking cookies together is a way of playing and to go shopping is also a form of playing. Crafting, drawing and cross words are also common forms of play to them.
Chapter 4:
Stripes
En randig sorg

Dyre Altegrov has been researching and writing about children grieving for more than twenty years now. In his book Sorg hos barn he wrote a chapter on what makes the grieve worse for children. It is mainly how the adults handle the situation that affects how children handle their grief. If adults are hiding or not giving information about the process and what is going on, children make up fantasies about what is going on. And fantasies are almost always worse than reality (Dyregrov 2009). On Cancerfondens homepage it is stated that a child participating in the situation when a close family member is sick, get trained in empathy and how to deal with life and also how being integrated makes them feel safe. As much as the act of keeping them away can create feelings of low self esteem and being unimportant, as much can the opposite feeling be created when they are integrated. They then feel that they are important and that they are trusted (Cancerfonden 2009). There is also a new law that has got a lot of attention lately that the care staff are obliged to inform the child about the situation when a parent is sick (Sydsvenska Dagbladet 2011).

Target 5-10 years of age

The main reason to choose the age group of 5-10 years is that children before five years of age does not understand that being dead is something definite (Dyregrov 1989). They believe that being dead is something that you can come out of, like you are on a holiday. The concept of what death is to children is determined by age but also depends on what experience they have from before (Ludvigsson 2005). It is at the age of five to ten that children starts to understand the notion of being dead. How children mature and understand death is obviously individual but in general children does not understand the concept of being alive until six or seven years of age (Dyregrov 1989). In the age of 7-10 years the Tom Sawyer syndrome is common where children get satisfaction and feel the need to understand how devastated parents, teachers and brothers and sisters would be if they died (Ludvigsson 2005).

Even small infants can sense an emotional situation as someone being very sick. Even if they don’t understand the context they react on the surroundings anxiety and emotional state. It is
suggested that even very small children should not be left out but integrated in the situation when somebody close is ill. It is also suggested to speak honestly but simple about the situation to pre school children enabling them to connect the dots. If they are not supported in this they might create their own story or connections to make sense out of the situation. It is common that children in the pre school age put themselves in the center of the universe and they can often find ways to blame themselves for a decease of a close family member (Cancerfonden 2009). Around the age of seven, children are eager to know facts and reason for things. They also develop a higher sense of empathy. It is also during this age that children can get very scared and affected by someone’s death and worry that people close to them also could die (ibid).

A five year old child said that “nu vill jag gå ut och leka jag tycker att vi varit ledsna för länge”, at the reception of his mothers funeral. Children grieve in individual ways and Rädda Barnen has made a video and wrote a book named Barns sorg är randig. Meaning that the grief is neither grey or black or white. Children move in and out of their grief and it is often their way to handle the situation and no value should be put into this behavior, as it is a natural mechanism (Rädda Barnen 2005).

There are various methods and artefacts that can support children in their grief when someone dies. As a state of the art in what children can do to talk about their grief is the memory book, that the staff at Axlagården offer to children and teen agers that are visiting; Så länge jag minns finns du written by Ida Gamborg Nielsen. You can collect objects, pictures and write down information about a close kindred who died or is dying (Gamborg,Nielsen 2006).
Chapter 5:
Methodology
Methodology

The word ‘experience’ has two (or three) definitions. Both as a verb and as a noun. It was a nice experience and from experience we learned that (Random house 2011). The methods have been chosen to fit both a design research approach and methods to evaluate and test the actual experience of the result.

An experience design process is often based upon close collaboration to get an understanding of the situation and several iterations each and everyone more refined to fill its purpose adequately. As this thesis is focusing on the relationship between the patient and child during a and visit in the complex situation of Palliativ Care, the methods have been chosen to get the different perspectives from the actors involved in the situation pre, actual and post experience. The execution of the methods have therefor been a parallel process where the outcome of the workshops with children have been synthesized and implemented and discussed with nurses and specialists.

Various methods were used during the project. ‘Predict next year’s headline’, where found insights are shaped into a future scenario of what visiting palliative care will be like in next year is a method from IDEO that could create an interesting outcome from discussing with nurses. ‘Inforcement’ is a method that combines ethnography and empathy where the first part consists of ethnography as e.g questioning and observations. Information found so far will be interpreted and with empathy for the users turned into pretending acts. This method is especially suitable in teams developing new types of products, as people have a hard time imagining entirely new product groups (Johnsson, Dishman, Laurel 2003 :pp. 39-54). Due to the relevance of the method, it could maybe be transformed slightly into a semi structured brainstorming session where the situation of sitting around the bed could be turned into an idea generation. To use this as a way of participatory experience prototype or as a brainstorm session having an actor/actress or role players acting out the behaviors a patient could have and brainstorming around it. By studying and looking at the actor/actress a possibly interesting co creation could happen. The plan is to invite designers to an ideation sessions like this where the later alternative is explored through a staged performance of sitting around the bed is being brainstormed around.
Observations

Participative academic ethnography can take years to perform in its best way as it aims to blend into its surroundings. (Plowman 2003 :pp.30-39) It was in this thesis done in condensed way. Observations where done during three different occasions in the palliative care units. During two occasions several days where spent to understand the situation and what the everyday is like in a Palliative care center. The aim was to be as participatory as possible and to involve in activities as meal and other social activities.

Interviews

To understand the system and who all the actors are that are involved in these processes several interviews was executed.

To gain insights and knowledge for the situation of being a relative and a patient in palliative care, nurses and social workers at Axlagården and Stockholms Sjukhem was interviewed on this matter. All the interviews took place in the palliative care unit except the relative interview that could place in their home. In formal interviews with teachers was executed to get the picture of their work and what they do and see in their everyday life after a close relative to a child died. They were except all executing in the school or kinder garden in relation to the workshop sessions. One interview took place in a teachers home. Parents was interviewed on what their children like to do that gives them comfort. They took place on the phone or in people’s homes.

Workshops

Workshops are condensed working sessions that need a clear aim and strategic planning how to strive towards the goal. They were carefully planned for different purposes; pure inspiration or specific insights.

Workshops was facilitated with children to gain inspiration for the project on how they like to play, what they think is important when you play and how you play with someone who is older. Two groups of children was participating on this during three different occasions. One younger where the children are about five to six years old in day care and one group in primary school aged
seven to nine. The workshops was constructed to be a dynamic mix of discussion and tasks. To make the children understand that their insights are very important the warm up was to fill in and complete ‘specialist’ signs with name, age and to put it on their shirts. They are the extended and most important team members of this project and it is important to treat them accordingly. The aim for my set up is to “make them feel like experts” and to “treat their views with the same respect you would show an adult research participant” as suggested as one of the basics in working with children in the IDEO Method Deck Junior Cards (IDEO 2010).

Pre school children

Five children were participating in the workshops at Slätterängnes Pre school, three girls and two boys all five years of age. Both the sessions lasted for about an hour in the midmorning and took place in the pre school. A teacher was participating and assisting during the sessions as she knows the children well.

What do you like to play with? & How do you play with a grown up or someone that is old? What is a book?

The first session was more like a brainstorm discussion with the children than a workshop. It was in two parts. The aim was to get to know the children and understand what children like to play with, how they play with elder people and how they feel about books. The session started out by explaining that their help was needed as they are specialists in playing and by them filling in their names on specialist badges (see fig. 7).

Fig. 7. Specialist badges to be used for the workshop
After the general play discussing the children were asked to bring their preferred toy for playing in pairs and we discussed why they were special to them.

The session moved onto a discussion about books. The explained what a book is and what you do with a book. They went and picked up their favorite book, explain what it is they like about it and show what they do with it (see fig. 8). The discussion moved onto a workshop where the children were making their dream books (see fig. 9). The session ended by the children explaining their books and a diploma ceremony where the children were thanked for their participation (see fig. 10 and 11).

![Fig. 8. Children showing and explaining how they interact with books.](image1)

![Fig. 9. Workshop where the children are making their dream books.](image2)

![Fig. 10. The dream books are laid out after the workshop session.](image3)
How do you play when one have to stay in bed?

During the second workshop session the children were again initially asked to create their badges but this time they had a white background and gave more space for the children to fill in what they felt like. Then they were asked to solve a problem. Through usage of a narrated story a problem about how you can play when someone is in bed. The narrated story has a basic framework that could be transformed depending on what the children said in previous session. As mentioned before, children in the age of five are very self centered and children in the age of seven are developing a higher degree of empathy, the narrative is built to suit these needs.
I want to tell you about Rut and Karl. Rut and Karl are good friends. Karl is almost always wearing his dotted scarf and Rut her red hat. Rut is 62 years old and Karl is 5 years old and they play together often. They play a little bit of everything. For example drawing, playing games, lego and reading books together. They think that is fun! Karl likes Star Wars and animal books and Rut likes to count things in the books.

When it was cold outside, Rut fell and broke her leg. Typical! Rut has a plaster and has to stay in bed and rest for 3 weeks. Karl and Rut have a problem now and they need our help. It is not as easy to play when one has to stay in bed. Do you know how they could play if one is in bed?

Like a role play session they are all imagining what it is like to have a broken leg or to sit around the bed. Props was used to support the narrative for this session to create excitement about the characters and empathy of the situation. A cast, a red hat and a dotted scarf was the main props to support the story and a blanket and some cushion to create the context (see fig. 12+13). The cast was made from soft fabric. By role playing and usage of a couple of selected toys the children were acting out how the problem could be solved in a suitable way.
Primary school children

The workshop with the primary school children took place at Ljunggrenska skolan in Trelleborg. It was midmorning and lasted for an hour. The benches were placed in two islands as they were at times collaborating on tasks.

The workshop with the primary school children had a slightly different set-up as they are both older and a larger amount of children. 14 children participated in the workshop. This session was more focused on writing and less crafty but their first task was to cut out the badge and then fill it in. The children got tasks to solve and the play subject was worked in three different ways; listing of top 10 games, discussing what is important when you play? and how do you play with someone who is 60 years of age? Lists were created for this session (see fig. 14).

To start the role-play session the same narrative with Rut and Karl was read out loud, now slightly

Fig. 13. Children role playing as the characters from the narrative and testing what you can play while someone has to stay in bed.
changed to fit their games and interest. The children were asked to write and draw their suggestions for how Rut and Karl could play (see fig. 15). Some of the children were participating in the role play and some were watching. The session ended by everyone saying their suggestions and showing their drawings. They each got a diploma as a thankyou for their participation.

Fig. 14. Children listing their top ten games

Fig. 15. A solution for how you can play when someone is bedridden from a primary school child.
**Workshop nurses and designers in a mix**

Workshops was facilitated when visiting Axlagården and with Stockholms Sjukhem. The set up and aim for these were very different from the ones with the children. The aim for these sessions was partly to get information about what visiting children and what their families do when they are in Palliative care today and if they see any problems or constraints in this situation and to quality check the content of the concept, and partly to quality check the project so far.

**Workshop Axlagården**

Three nurses and one friend participated in the workshop session that took place at Axlagården early afternoon for one hour.

The first task was to list ten activities the patient and the relatives do together during a visit, then completing with artifacts and finally problems or constraints in the situation. A form was prepared for this task to be filled and folded (see fig.16).
A brainstorm on the topic what would you do for the guest and its family if you had limited resources for year was facilitated with post-its to warm up and prepare for the next creative task. Every time someone had an idea they would say it out loud and put the post-it on the table (see fig 17.).

As a last task was the method ‘Predict next years headline’ (IDEO 2009). Dagens Nyheter functioned as the foundation where some of the content was manipulated and white spaces left out for the participants to fill in text and pictures. The participants were asked to fill in the story they think will be on the headline in a year if it was about them and the work they fictionally did for the patients and their families for a year with unlimited resources (fig.18).

![Brainstorm session on what the nurses would do if they had unlimited resources for a year.](image)

*Fig. 17. Brainstorm session on what the nurses would do if they had unlimited resources for a year.*
Nurses and Designer friends 24/3-2011

The workshop took place after hours at Konstfack. The aim for this session was to get feedback on the process and to enrich the existing content and feel of the activities in the concept. The session was shaped aiming to function as a ‘hot group’ where nurses and designers work together for an hour (Kelley 2001). Three methods from the IDEO method cards was combined in this session with staff from Stockholms Sjukhem and designers; Role Playing, Experience prototype and Quick and Dirty Prototyping (IDEO 2003). As this session is mix of designers and nurses, role playing
was chosen as it can put the participants on the same page and the team can trigger empathy for actual users and raise other relevant issues (ibid). Input from the children and interviews were implemented in the concept and a quick prototype was made out of paper for the participants to test it out as an experience prototype while given the roles of either the patient or the visiting child.

Two designers one nurse, Helena Leveälätha, and Emma Stenström, second advisor for this thesis participated in a workshop session. The aim for this session was to quality check the synthesized version through a role played experienced prototype. The set up for the session started with a short description of what has happened in the process so far. The participants were asked to draw their own game character and then moving onto the experience prototyping session where the participants tried out the concept and co-created how it could be done even better. In the same way as with the children a narrative was presented to put them in the situation and they were each given roles of either the two children, their grandmother receiving palliative care or their mother, in a visit (see fig. 19). The version of the prototype was a very rough paper prototype for the participators to feel comfortable to co create and criticize freely.

Fig. 19. Workshop session at Konstfack aiming to quality check the content.
Interview testing game 10/4-2011

To develop the insights from the children, an interview with an eight year old girl was made in her home environment. This setting is very different from having a workshop in a kindergarten or in a school. She showed her room, toys and explained about play. Her favorite toy is the pet shop. She showed them to me and how she plays with them. She groups them in families in colour scales. When she plays with a friend they play with the pet shops or craft and draw. We talk about what is important when you play and she says that the most important is that everyone thinks the game is good and that you can be many to play not just two people. She has put a lot of work into a making a post box that she shows me. It has one big slot for big mails and a small on the top for small letters.

A rough prototype of a game idea was later tested out. The game is built up with small tasks and questions aiming to create discussions and an exchange of personal information. E.g one task is to guess how many teeth you have and one is to tie a rosette. The session started out by drawing our own characters. Her mother was placed in bed and she and another person was sitting on the side of the bed while test plying the game (see fig. 20). After the game a discussion about the game took place.

Fig. 20. Game testing session with an eight year old girl and her mother.
6.0 Result
Criteria/function analysis

The result of this research project is embodied in BäddBoken a working prototype that is ready to be tested out in its real context. Every little question and shape has a purpose and reason for being the way they are. From research the following criteria are described in the functional analysis below.

MF
be suitable for both the patient and child

N
be hygienic and washable in 60 degrees
be customizable to certain degree
encourage conversations
be mountable on the bed
build stories
produce
encourage a co creation
work for many children
create a nice moment

D
be aesthetically appealing
have various tactility’s
engage haptic
work over time
work on different levels
Object details

Due to hygiene and standard of the care units the object has to be washed in 60 degrees and that has been a main factor in choosing the material. From speaking to art and occupational therapist the tactility becomes evident and a desirable aspect in the piece. The cover of the book is made out of velvet in this case turquoise with over dimensioned red manchester binding and details. The colour and material we surround ourselves with affects us. Turquoise has a soothing effect giving connotations to the sky and the sea. Red has many associations; passion warmth and love among others. The colours are chosen to give an interesting yet unprovoked impression (see fig. 21).

![Fig. 21. Colour combination](image)

The name and logotype of the project is printed in black on the cover of the book. As the velvet has a fringe the technique used for this is reactive type colour that dyes the material. The pages are made out of organic satin with golden and black print. The choice of gold came from meeting the children. When the children made their own books it became evident how they were especially interested in shimmer. Which was also confirmed by their teacher. Gold feels special and magic to them. Gold also has the advantage of being gender neutral. All the movable pieces have velcro attached to them. In case of a bigger edition the colour of the cover could vary but always aiming to be gender neutral. If there are many books in a unit the variations could be bolder as the are a matter of choice (see fig. 21).
Binding

For the piece to be as customizable as possible the binding is constructed with press buttons. This version has four pages. For patients that lived in other countries a world map is needed. The advantages with a flexible binding is that pages can be taken out and the book can then be made to suit different needs and ages (see fig. 22). The whole book or individual pages can all be hanged on any hook when not in use.
Activity

All the activities in BäddBoken come directly or indirectly from meeting, talking and co-creating with the different actors in the situation. Children, their teachers, the nurses, occupational therapist and social welfare officers among others. Some of the pages have activities that are purely for fun like the shaping art page and some are aiming to encourage a telling of life stories or times shared. The map with movable symbols could for example create a discussion about where we are now, then and about where life has been spent so far. This type of interaction could be triggered by the pins marked with ‘now’ and with ‘then’. Some of the pins are empty to give the option of marking whatever you want and feel like.

The game page has a traditional noughts and crosses in the middle. The x and o’s are printed in gold and are attached with velcro. Surrounding this is a frame of squares with questions that form another game. The questions follow various themes. One question is ‘how many teeth do you have?’ another one is to ‘tell your first memory!’ They are all posed in a way to encourage the participants to talk about themselves and each other, building up excitement. There are no rules of the game. The reason for that is that the condition of a patient varies and for some two questions could be enough and for some you might want to do them all. There is no right or wrong. The game pieces are on the right side. There are six of them, a dinosaur, a flower, a birthday cake, a star, a hat and a traditional piece. They come from test playing the game where the participants were to choose their own piece to play with if they were to choose (see fig. 23).

Fig. 23. Game page and post box
The page with symbols and words can be used to create sentences, building a story or to explain how you feel. The words have gone through several iterations and tests before being the ones they are (see fig. 24a and b).

Fig. 24a. Three generations discussing and organizing the words and symbols.

Fig. 24b. Close up of the word and symbol page.
**Bertil**

A protagonist has the function of a main character leading you through. Bertil is the character of BäddBoken. He might come off as an animal angel. He has a white horse like body and wings or fins. They are undefined since we actually do not know what happens to us when we die. He has a golden nose. A nose that just might be able to activate things with or maybe it is magic. He is present on each page of the piece. On the side above, below or on the side. He never disturbs the activity but is always around. Sometimes hinting on the activity and sometimes he is just there relaxing or watching.

As the character could be perceived as cute and angel like a contrasting name was chosen for it to give it a different dimension and impact. He was given the name Bertil as his only name. The name Bertil sprung from the german word ‘berth’ meaning shine and light. Bertil was popular in the twenties and thirties but has decreased ever since and in 2003 only one child got Bertil main given name (svenskanamn.se 2009). Today there are 68263 with Bertil as their given name in Sweden, one of these a woman. 14809 are using it as their first name (scb 2008). The consequences of the use of the name is that people named Bertil are now often men in their eighties and as the popularity of names often go in cycles Bertil might just o be popular for babies soon again. This fact makes the name even more suitable in this context.

---

*Fig. 25.* Bertil the character
Size

The size of the book is 100 cm wide and 80 cm high. The reason for the size is to fit the bed on the width and the height should both suit both one or two kindred on the side and offer good legibility for the patient. It was the double on the height of the beginning but was continuously decreased for legibility and to create an non excluding situation (see fig. 26).

Type

The font used in the book is chapparal together with hand written details and illustartions. It is chosen as it has a child like feeling to it without being silly. It also has a good legibility which is important in this situation. The size of the font is 50 and 34 for sentences and 150 for individual words. The font is also used in the logotype but with less spacing.
Construction

There is a function of having the weight of the book directly on a patient. In the same way as as ‘Bolltäcket’ is used to calm patients down. But it can also be uncomfortable to have an object on top and as many patients can be sensitive at the end of life and even a light stroke can be uncomfortable, there must be an opportunity for the book to be attached on the rods of the bed instead of lying directly on the body.

The beds look different in Axlagården and in Stockholms Sjukhem (see fig. 27 and 28). The measurements vary slightly and the rods look different. During the feedback session at Axlagården with the nurses the solution of using the rods of the bed was confirmed. At Axlagården the beds are one meter wide and have rods in shape of a plank circumferenced twenty one centimeters (see fig. 29). At Stockholms Sjukhem the beds are ninetyseven centimeters wide and have round shaped rods with a circumference of eight and a half centimeter (see fig. 30). A flexible solution to fit them both is needed. To fit both the circumference and width of the bed a velcro solution was sketched and tried out (see fig. 31 and 32).

Fig. 27. The bed at Axlagården.

Fig. 28. The bed at Stockholms Sjukhem.

Fig. 29. The rods at Axlagården.

Fig. 30. The rods at Stockholms Sjukhem.
The end of the velcro piece you will interact with while attaching the bed was sketched out in 2D (see fig. 33).
The solution is a velcro piece you strap around the rods, in the ring and attach it on itself. As it goes over the rod and around it can be firmly attached and give good space for patients that are uncomfortable with heat or weight (see fig. 33 and 34).

Fig. 34. BäddBoken being attached on the rods of the bed by a nurse.

Fig. 34. BäddBoken being attached on the rods of the bed.
Chapter 7:
Discussion
BäddBoken is a concept purposely made to function in a palliative care context. Through a participatory approach aiming to involve all the actors, all content and details are designed for the situation of a child visiting a close relative in a palliative care unit.

BäddBoken is just one example of how a visiting child could be included in the situation. It has focused on the situation of a visit. It could easily be extended in various ways to help and support the child in their grief both before during after the patient is in palliative care. Crafting kits, poetic discussion tables, special side beds and seating to be mounted on the bed are just a few other ideas of what could be done in the situation. Many other things could be done to give comfort to the family in the situation. Just by putting effort into doing anything small or big will make a difference to people in the situation as small things and sentences and smells can stay in the memory forever. A purpose made pattern for the situation could easily be made an used in the context.

The directed process, used methods and workshops facilitated have all together ended up and been embedded into the piece in different ways. The collaborations have been both challenging and fruitful. The combination of the methods involves actors which seems relevant and satisfying. Obviously best case scenario would have been to collaborate with the main actors. But since the nurses know see the situation as their everyday reality their input felt reliable. Some of the workshop sessions worked extremely well and some did not achieve the planned outcome for various reasons. In general, the collaboration with the children worked well. The narrative suited and engaged the children and they enjoyed the role playing sessions. A key factor for this success was probably that their teacher was present as they know the children and could help facilitate the sessions.

The workshop with the nurses at Axlagården during working hours dealing with the current situation and future dream scenario didn’t work out as well which was evident in the results. The first task worked smoothly and was informative. The outcome of the two other tasks had little to do with the perspective from the family and was more about the whole palliative care situation and working environment. This could have been influenced by the fact that the session took place in the care unit or that the sessions was not directed properly.

The workshop with the designers, nurse and advisor was a suitable combination that resulted in a productive session with a lot of valuable input and co-creative work. The symbol page, map page,
game page and post page was considered the most relevant and suitable for the situation and they have all been refined on a detailed level regarding the experience and its functional aspect. On the game page the rules and start/goal was taken away. It is better and funnier to make up your way of playing and your own rules - this also follows in line with what the 8 year old girl preferred. Also as the condition of the patient varies this makes the time aspect more flexible. More symbols were required. The map page that was a blank outlined shape of Sweden was co-created successfully with drawings. The participants spoke about an animal park, where they live, where friends live, where Greece is situated, skiing vacations, where we were born, were grandma lived before.

The session was very fruitful and the experienced activities were discussed in a qualitative way and some crucial decisions made. The format of the object got a bit smaller on height to 80 cm instead of 100cm.
Chapter 8:

Conclusion
In order to offer relief to the relatives, the patient and especially the child, an including and interactive solution have been created for the relatives. BäddBoken contains various activities that can take place around the bed when a child is visiting that builds upon existing relationship. From a co-creative and mainly participatory process, different actors in the context have been involved to quality check the project and make it appropriate. Being appropriate have been key for this project. What was suitable in everyday life might not at all be suitable in a palliative care situation. Everything is different. The project has had to constantly be made flexible to not be intrusive following the set criteria to be just that; Appropriate.

The project has not yet been tested in its real context and can therefor not yet be properly evaluated. From meetings and discussions with staff and nurses from the palliative care units the quality of the project have been confirmed. They find it suitable to use in the context and that it fulfills the purpose. They want to try how it is received and implement ‘BäddBoken’ as a way to help patients and children to communicate and build upon an existing relationship at the end of life during a visit.
Chapter 9:
Recommendations
BäddBoken is now ready to be tested in its real context. Some details in material properties needs to be tested and the plan is to make a couple of prototypes and see how they are received in the palliative care units. A test round followed by an evaluation to sum up and see what worked and how it could be improved.

When presenting the new prototype to care professors and to the nurses an interesting discussion happens. They are all eager to try it out. They see the project suiting a broader audience such as children’s hospitals and geriatric care. For that scenario to happen the content and intentional interactions will have to be revised. A strength of the project today is just the fact that it is purpose-made for a specific situation. For the object and interactions to remain valuable and concise, other processes and collaborations must take place. BäddBoken could in that case turn into a library of shared activities in various hospital environments.

When BäddBoken would be introduced to the patient by an assistant nurse or nurse a folder showing the different page options would make most sense. A folder that clearly could explains how BäddBoken could be used and what pages could suit their situation.

Other projects for children, teenagers and kindred in general would definitely be desirable for this context. As Professor of Nursing, Carol Tishelman said in her palliative care lecture at Konstfack in December 2010, “anything you can do to make it easier for the family is good”.
References


Online resources


“Var Döt De äldre – På Sjukhus, Särskilt Boende Eller Hemma? - En Registerstudie.”


**Bibliography**

**Book on children grieving**


**Books for children about death**


**General Palliativ Care literature**

**Online lectures**

Theater

Movies


Novels