

PATH OF STORIES

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ABSTRACT

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This is a product thesis. The aim of the thesis is to produce Path of Stories exhibition with Sanervakoti participants about so called stimulating activity using painting as creative method. Sanervakoti is an intense assisted accommodation for people with memory illnesses and it is operated by Helsinki Diaconess Institute. This thesis also gives information on how stimulating activity is operating at Sanervakoti and how it affects the residents. In order to deepen the understanding about stimulating activity, the effects and challenges at Sanervakoti, I also interviewed three staff members. The interviews and production of the exhibition were done at Community Empowerment and Participation placement period during five weeks in September and October 2015.

I observed and facilitated stimulating activity and the creation of paintings by the residents for Path of Stories (Tarinoiden Polku) project, which is part of a larger community project Tarinoiden Myllypuro. I conducted unstructured interviews for a social instructor, nurse and practical nurse in order to include the views from representatives of all professions. The exhibition took place at Community House Mylläri, Myllypuro, from 1st until 26th of February 2016. During the exhibition, viewers left comments of how he/she experienced the paintings.

Keywords: Participation, Empowerment, Stimulating activity

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1. INTRODUCTION

The process of Path of Stories, interviews and observations are parts of the production of the thesis, which is connected to Tarinoiden Myllypuro project. Tarinoiden Myllypuro is an active on-going community development and multicultural enhancement project. For production of my thesis, I chose to include inhabitants of Sanervakoti in stimulating activity for creative work using painting as the method for self-expression.

I begin to open the topic in chapter 4 by introducing some ethical issues related to working with people with memory illnesses. Nowadays, stimulating activity has wider attention regarding social work at care units. However, stimulating activity have been used in care institutions for years. The activity is usually singing, painting, baking, playing games and so on. There has been articles and researches of the effects of stimulating activity for the individual level and to the community at large. In chapter 5, I explain how stimulating activity is operated at Sanervakoti. By reporting the results of the stimulating activity as well as staff members experiences, new methods might be implemented into daily life and perhaps new insights might appear.

The process of the Path of Stories is explained in the chapter 7 as well as the connection with community work. For deepening the understanding of the stimulating activity, I also interviewed 3 staff members. The results of this thesis present evidence of how values of Sanervakoti are implemented through stimulating activity so that it will promote well-being of the residents. When a person is experiencing fulfillment through the pleasant activity it has effects on how one perceive others as well. For people with memory illnesses, the stimulating activity has been noticed to be highly beneficial as it also supports the functional capacity of the individual. The interview findings are combined in the chapter 8. This thesis emphasizes the meaning of empowerment and participation for well-being of the residents and staff members, who together create sense of community at Sanervakoti.

2. SANERVA-KOTI

According to the Sanervakoti goals, home-like environment, safety and communality are the core values. Sanervakoti is located in Myllypuro, eastern part of Helsinki. It is organized by Helsinki Diaconess Institute. Sanervakoti operates for citizens of Helsinki under 65 years of age, with memory illnesses or decreased functional capacity and was founded in 2005.

The capacity in Sanervakoti is for 49 residents. According to the Lead instructor, Sanervakoti operate in order to promote participation, maintain and increase functional capacity, control of the illnesses, control and decrease of the behaviour symptoms of the residents.

Sanervakoti provide 24 hour care and support and collaborates with municipal healthcare personnel. The staff members are consisted of 30 practical nurses, 8 nurses and 2 social instructors. Sanervakoti has history as an institution for substance abuse clients. Therefore from the eyes of the inhabitants of Myllypuro, Sanervakoti has an image of an institution of the excluded. However, most of the people of alcohol and drug use history have moved to Alppikatu premises. The main diagnoses of the residents are memory illnesses such as Frontotemporal Dementia and Alzheimer's disease. These conditions creates special demands and high skilled staff members.

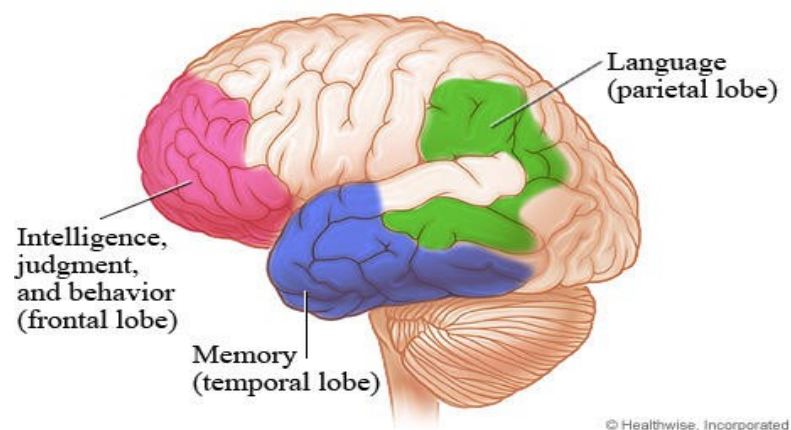
The main nature of the work is care work, which the residents require in order to live everyday life. The main profession is practical nurse. Stimulating activity has increased over the last year and it is becoming a natural part of the everyday life for residents of Sanervakoti. Stimulating activity, offer and encourage residents to do what they find pleasant in order to reduce the level of stress and depression, which are caused by dementia and Alzheimer.

Detailed understanding of the behavioural and psychological symptoms such as social disturbed behaviour, apathy and aggression helps the personnel to manage every day challenging situations and facilitation of stimulating activity (Cox 2007, 55).

As Ledwith (2005, 63-69) explained that the decreased sense of self-esteem, rise aggression and confusion. However, if the person is treated with respect and dignity, it can be transformed into confidence. The values of Sanervakoti in order to promote participation and decrease the behaviour symptoms of the residents are essential for empowerment and enhance learning of the residents.

3.WORKING WITH PEOPLE WITH MEMORY ILLNESSES AND DECREASED FUNTIONAL CAPACITY

At Sanervakoti, dementia is the main diagnose of the residents. According to Cox, (2007, 4) dementia is not a disease, it is rather a set of signs, which has an effect on persons capability to operate in daily living. Although it has impacts on cognitive activity such as thinking, remembering and reasoning. Obviously these signs causes transformations in behavior and personality. At this chapter, I introduce two types of memory-illnesses, Frontotemporal dementia and Alzheimer's disease as well as explain the causes and effects because those are the dominating diagnoses for residents at Sanervakoti.



PICTURE 1. AREAS OF THE BRAIN AFFECTED BY ALZHEIMER AND OTHER DEMENTIA

Picture 1. present different parts of the brain and their function for memory, behavior and language. There are several dementia-types, and one of those is Frontotemporal Dementia (FTD).

3.1 Frontotemporal Dementia

According to Holland & Krucik (2013), this type of dementia cause disorders at frontal and temporal parts of the brain. The frontal and temporal lobes function for judgement, behavior and memory. Alzheimer Association (2016) explained the reasons for the disorders are proteins Tau and TDP43, which damages the nerve cells. Frontotemporal dementia is caused by a damage to a frontal lobe or temporal lobe (Weale, 2009, 6). Hughes (2011, 64) stresses that the effects in the behavior for person of Frontotemporal Dementia, are repetitive speech and behaviour, propensity to place items in the mouth and incontinence.

Working with people of memory illnesses creates special demands from the staff members and social instructor. However, when the staff members are aware of these symptoms, they are able to find suitable communication methods with the residents.

3.2 Alzheimer's disease

Munoz and Feldman (2000, 65) explained the causality of developing Alzheimer's disease is the rare mutations in three genes as well as excessed amount of beta-amyloid protein in the brain. The effect is that it will block communication in the brain cells and then cause failure. The behaviour effects appear in a way that an individual has problems in language, is confused and lose realisation of time and place (Alzheimer's Association, 2016). As the cognitive activity changes, it will cause stress and commonly depression for the person. This combination affects for ability to function and how they experience the world (Cox, 2007, 7-14).

According to Reisberg (2016) list of Clinical stages of Alzheimer's, the stages are as follows:

1. Normal: A person is mentally healthy and free from symptoms.
2. Normal aged forgetfulness: People over 65, experience cognitive or functional difficulties which appears in difficulty of concentration.
3. Mild cognitive impairment: The symptoms are anxiety of not being able to perform daily routines as they used to. At this stage psychological stress increase and the stage can last for two to four years.
4. Mild Alzheimer's disease: At this stage the ability to manage complex activities decrease such as managing finances and prepare a meal. The dominant symptom is withdrawal.
5. Moderate Alzheimer's disease: A person can no longer manage by themselves and need assistance in eating and dressing. This stage can last for one and half year.
6. Moderately severe Alzheimer's disease: All five sub stages are identified. At this stage person lose ability to manage independently to use toilet. Misidentify people such as family members. The emotional causalities are feelings of fear, frustration and shame regarding their circumstance. This frustration can burst out in form of violence.
7. Severe Alzheimer's disease: At this stage a person require continuous assistance with basic activities daily. The symptoms are limited speech, lose ability to smile, increase rigidity in the body and require support to sit up.

3.3 Person-centred approach related to stimulating activity at dementia care

Johnson, Walmsley and Wolf (2010, 127) brought out the aspect of person-centred care or individualised planning, which ultimate purpose is to focus on holistic, emotional and spiritual needs. These needs can often be seen as not particularly relevant in task-oriented care institution.

Brooker (2006, 12) presented for the person-centred dementia care four essential elements, which are described:

1. The significant component originates from valuing the people
2. People need to be treated as individuals.
3. Empathy towards the people with dementia stands for ability to see things from their perspective.
4. The social environment needs to be created in positive sense.

In my opinion, these principles can work as a ground rule in any care unit for stimulating activity. However, because of the hectic nature of the care work, these conditions can easily have lesser attention, and the work can become task-orientated. Wide capacity of empathy and communication with respect, are the qualities that the staff members at a care unit for people of memory illnesses have to possess, because it decrease the aggression and confusion of the resident. Organisational power relations also have an effect on the residents. When equality and respect for one another are practiced, then it will lessen stress not only from the staff members but as well from the residents.

4. ETHICAL ISSUES REGARDING SOCIAL WORK AND PEOPLE WITH MEMORY ILLNESSES

I find it relevant to explain the ethics regarding people with memory illnesses, because they are a group of vulnerable people as they have a decreased ability to make decisions regarding their own life and also are in a risk of abuse. Ojakoski and Ronkainen (2011, 19) explained the purpose of the ethics is to address values and the choices which are related to ethics and well as those stands for manners, which is referred also to morals of ethical norms. The ethics have very important function in our society and especially in the care institutions.

Human rights, liberties and rights of an individual are in the Constitution of Finland, in order to protect guarantee and promote justice in the society (Paunio, 2005, 1). However, ethics and people with memory illnesses have special demands regarding self-determination. Regarding ethical issues related to this product thesis, the main emphasis is the participation of the resident to the stimulating activity. The resident has a right to participate to the communal event such as stimulating activity, even though one might not be active on it. Having the right to be included to the community and into a group, will itself promote social justice and the self-determination.

4.1 Self-determination of a person with memory illness and relation to well-being

Self-determination is part of the liberty of an individual. The basis on the Act on the Status and Rights of Patient 785/1992 is that the wish of a resident/patient has to be heard and respected, including those who are not capable of deciding matters regarding their own care (Paunio, 2005, 5-6). Therefore, the challenges on issues related to the self-determination occurs in a situation when a resident/patient is not capable to express their will and opinion.

People with dementia and Alzheimer therefore are dependent on other people regarding the decision making. However according to Remmers (2010, 203) stated that the dependency does not automatically mean incapacity of self-determination. It means that self-determination has to be operationalised differently in respect of potentially restricted conditions of life. The most important is to guarantee safety of the resident. This leads to an aspect of well-being. Weale (2009, 28) states:

“A person with dementia clearly has an interest in being helped to maximise their well-being, an important aspect of which will be related to the satisfaction of their desires and preferences”.

The activities and communication with staff members and other residents that occurs during a day, have a direct impact on resident's well-being. Hasselkus (1997, 432) cited Kitwood and Bredin (1992) about the indicators of well-being of people of dementia. They described the list as follows:

“The assertion of desire or will, the ability to express a range of emotions, initiation of social contact, affectional warmth, social sensitivity, self-respect, and acceptance of other persons with dementia, humour, creativity and self-expression, ability to show evident pleasure, helpfulness, and relaxation”.

5. THE STIMULATING ACTIVITY AT SANERVAKOTI

Stimulating activity functioned at Sanervakoti less frequently before 2015. They had Meno-maanantai and Toiminta-torstai (both refers to action), which were easy to organize because it happened only two times a week and could include most of the inhabitants. Sanervakoti participated in Art meets Care-project during 2008-2011, which objective was to offer art-based methods for work communities. At Art meet Care-project, Kirsi Heimonen, offered movement improvisation sessions together with the staff members and the inhabitants.

According to the article, Heimonen (2011, 42) explained the interconnectedness between the residents and the staff members. Experiencing together something unusual can increase mutual understanding and trust. Heimonen also highlighted the purpose of the art based methods at work community, is to discover new resources from individuals and therefore strengthen the community. Art-based methods may also deepen presence within and the communication with each other.

In the beginning of 2015, Sanervakoti Board ordered that stimulating activity should take place from Monday to Friday and all the residents need to take part into some club activity. Therefore social instructor, who worked at that time created clubs such as music and singing, carpenter, games and painting and decorated special rooms for their operation.

The methods regarding community development and participation of the individuals are mainly stimulating group activity, which takes place from Monday to Friday in the afternoons. The interviews bring out the discourse that empowerment in Sanervakoti appears in a group rather than promoting self-empowerment, which demands understanding and responsibility of one's own actions. The difference between group empowerment and self-empowerment is that people with dementia, cannot be demanded to fully practice empowerment themselves. They need to be guided and encouraged for participation.

Practical nurses along with the supervisor are in responsible to find suitable activity for each inhabitant, so that it would increase well-being for the individual. According to the Lead instructor, inhabitants also have personal time with their own staff member every day. This support the person's social functional capacity. The daily routine of dining together support as maintaining community spirit and social inclusion.

From the previous experiences of stimulating activity at Sanervakoti, the participation of the inhabitants had been challenging, because of the lack of motivation to take part. In order to motivate participation, it is necessary to include the participants into planning of the activities, which means when working with people of dementia to recognize their individual preferences. As Martin (2003, 157) explained, that seeing the vision in action when developing a new community work methods, the will to participate increase, even they might not be eager to take part.

According to Wegerer (2014) the Stimulating activities for Alzheimer patients are singing and playing music, art such as painting and knitting, cleaning or sweeping the tables or do some other household tasks. The suggestion stands for finding individualized activity that is suitable for the particular person. Siitonen (1999, 6) explained accurately:

“Empowerment is a process that starts with the individual him/herself and is connected to the individual's own will, setting one's own goals and trusting one's own possibilities and views of oneself and one's own efficiency”.

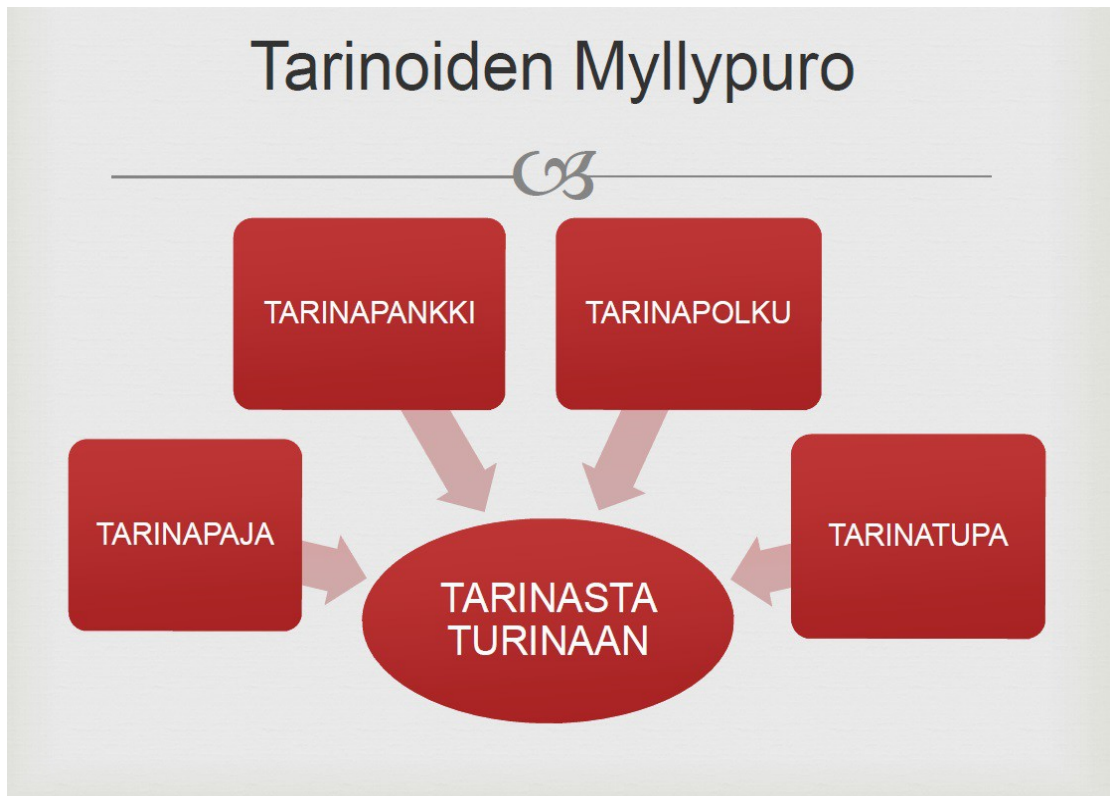
6. INTRODUCTION OF STORIES OF MYLLYPURO

Tarinoiden Myllypuro (The Stories of Myllypuro) project began in spring 2015. At that time I was doing my Building Society in Diversity practical placement at Community House Mylläri / Helsinki City Local Work Unit in Myllypuro. I was invited to co-produce material for the project in a form of thesis. Therefore I chose to use painting as stimulating activity as creative method in social service sector and found collaborative organisation Sanervakoti to participate into the project.

The role for the Path of Stories is to promote Sanervakoti through art for the inhabitants of Myllypuro. The exhibition also will increase the recognisability of Sanervakoti as an organisation of Helsinki Diaconess Institute for the residents in Myllypuro. Tarinoiden Myllypuro project's original vision is to increase communication with the residents of Myllypuro.

The objectives are collecting and introducing stories from the inhabitants. The stories are collected from interviews, discussion workshops and other communal events. The stories have been recorded, filmed or done by using other creative methods such as painting and photography. The documents are saved into a story bank, which is monitored at Community House Mylläri. Tarinoiden Myllypuro has a Facebook page, which is updated regularly.

The goal of the Tarinoiden Myllypuro project is to strengthen local identity for inhabitants of Myllypuro as well as give voice for the ones who have been heard less. This way people can begin to know more the area where they live in and share stories that would have an impact on the inhabitants.



PICTURE 2. THE VISION OF TARINOIDEN MYLLYPURO

7. THE PROCESS OF THE PATH OF STORIES



PICTURE 3. THE PROCESS OF THE PATH OF STORIES

7.1 Methodology and main concepts

The main focus of this study are the concepts of empowerment and participation and how do the stimulating activities increase the well-being of the residents. The chosen method is participatory which involved Sanervakoti residents to create paintings for Path of Stories.

All sessions were observed, documented and analyzed. I observed the sessions in order to see the change among the participants during and after the activities as well as interviewed staff members about the change. This product thesis give information of how stimulating activity is practiced at care unit for people of memory illnesses while recognizing the needs of the residents by implementing the values of the organization.

I conducted unstructured interview questions that were open ended and were designed to give information from everyday situations of the working environment. The observations and interviews present how the values of Sanervakoti are applied into practice.

Chamberlain (2013) explained at the article of A Working Definition of Empowerment, various dimensions regarding empowerment and mental health patients. One of the goals of empowerment is to increase one's own self image in a way that a person becomes more confident and capable. Thompson (2007, 27) also emphasised that by revealing power from within, it will increase self-esteem and can transform negative self-image.

Siitonen (1999, 117) explained about empowerment theory, that it is an internal process, which is connected to the desire of a person to trust one's own capabilities. Therefore the power cannot be given to anyone. A person needs to have desire first to discover own potential. Siitonen (1999, 94) also pointed out that a good facilitator/teacher has ability to bring out that potential from other people. However it requires that the facilitator/teacher has empowered one-self first.

This aspect leads to theory of self-empowerment, which is explained by Thompson (2007, 34-36). Thompson brought out that a person need to have internal confidence that one has control of their work and the situation where they are. There is a need for placing the self-empowerment context into care unit, where the nature of the work is often task-oriented and employee's experience that they only follow the orders. Because of the stress they face at work, the communication with co-workers can be disempowering and even hostile. If a staff member feels that one does not have power of their situation, therefore it directly will be manifested as low tolerance of pressure. The low tolerance increase stress levels and may cause burn-outs. It is fundamentally a responsibility and professional competence of a supervisor to support and promote self-empowerment of the staff members.

Ledwith (2005, 54) explained Paulo Freire's theory in relation to critical pedagogy, that the educator also learns and the learner also teaches. This equal relationship between facilitator and learner / participator gives opportunity to experience interconnectedness without dominating one another. Therefore, in my opinion, it gives freedom for both sides to learn and to teach. Paulo Freire (1921 – 1997) was a Brazilian philosopher of critical pedagogy and one of the first internationally known educational thinkers (Steiner, Krank, McLaren, Bahruth 2004, 2). I found Paulo Freire's approach relevant in order to implement the empowerment theory in education-learner roles, which are equal to each other Ledwith 2005, 54). Eriksson and Markström (2004, 17) introduced the core ideology of Freire's teaching, that he emphasised education of liberation, dialogue, cultural synthesis, reflective action and critical consciousness. As Milner and O'Byrne (2009, 237) explained, the empowerment should be applied into practice by showing interest of the strengths of the individual.

By encouraging the participants to discover their own abilities, it naturally empower as the individuals are treated with respect and dignity. This also leads

to promotion of social justice. Practical examples of this implementation are documented from the observations and the staff interviews.

7.2 Planning the sessions

The plan for the process of the Path of Stories was to try different forms of painting texture at each session. This was significant experiment as it gave information about the participant's functional capacity and how they experienced the process. Each session was planned ahead and previous sessions were taking into notice. The painting equipment were placed in advance, so that the participants were able to begin immediately when the session started.

7.3 Painting Part 1.

Tue 6th Oct, at 13:30-14:20

Present: 3 men

In the beginning, I chose to play on cd sounds from nature for creating a relaxing atmosphere. This seemed to make the participants feel at ease. Kinematic challenges occurred at the four stages. There were specific kinematic functions, which needed to take place before moving the paintbrush in the paper. First, drop the brush into water. Second, move the brush from water. Third, choose a color and roll the brush in it. Forth, move the colored brush into paper.

The participants were all very concentrated on the activity and wanted to perform the task on their own. One participant wrote same words all over again with red paint only. Another investigated thoroughly about the color combination he wanted to achieve and functioned with sharpness and very slow tempo.

Third participant found round large lines and repeated the same curve with blue and light blue. He was assisted to add color as he did not do it himself. He was truly immersed by the movement of the brush and the mark it made, and was willing to continue, when the others were ready to finish. The activity lasted altogether 40 minutes.



PICTURE 4. PAINTING FROM THE FIRST SESSION

7.4 Painting Part 2.

19th Oct, at 13:30-14:30

Present: 1 woman, 2 men

10 singing / following the music.

This time we decided to connect singing and painting together. We had already placed painting equipment, so that it was ready just to start painting. I had purchased finger paint for testing, how it would work differently than just traditional water paint. The inhabitants could not although realize that the paint was supposed to be done with fingers, not with a brush. So they used the paint as ordinary water paint. First time a male inhabitant was painting and he seemed to like it. He could be sensed as carefree at the time. Another female participant had been painting before and was truly enjoying the movement of the brush.

An older man in a wheelchair experiment the painting activity. He tends to have repetitive movements, and could not stay still. However he began to paint with intensive focus and could last up to 20 minutes. Then he decided to start eating the brush instead. This time, when focus was divided to singing and painting and the concentration was not intense at all times, the paintings were easy and light.

It was good to have the other activity as well, so there was not any pressure of producing anything, rather letting the painting flow freely. The manifestation of enjoying the activity was when they sang together “Rakastan elämää” (I love life) while proceeding with the paintings.



PICTURE 5. PAINTING FROM THE SECOND SESSION

7.5 Painting Part 3.

Tue 20th Oct, at 13:30-14:20

Present: 2 women, 5 men

The amount of the participants rose every time. Like at the previous session, we organized the painting equipment ready, so that inhabitants would sit down and start to paint immediately. It was delightful to see new faces in the club. The colors that were chosen were bright and at most of the paintings, sun was shining. A woman, who arrived first time to the session, sat quietly about 30 minutes, then she began to draw outlines of her hand. She was delightful and full of laughter.

Few men were obviously confused what to paint, as they did not have any idea. The music background this time was chosen to be Basso radio, which did create easy, careless atmosphere. Some inhabitants just participated, even though they did not want to paint. It is important to be able to participate and be present, even though a resident only want to sit, watch and listen.

The session lasted about 50 minutes, and participants left, once they had felt they were finished with the work. A truly invigorating break for the day.



PICTURE 6. PAINTING FROM THE THIRD SESSION

7.6 Path of Stories, community work and feedback from the viewers

Path of Stories was not an ordinary exhibition in a sense that the paintings were not done by a professional artist. The purpose of the exhibition was to give space for people who are outside the society and freedom to express their feelings in public space through painting.

Regarding community work and this product thesis, the connection is manifested at the exhibition. The purpose of implementing Path of Stories, according to Larsen (2013, 160-163), using art as participatory community work method in public spaces, gives spot for "silenced" group of people. Therefore it functions against stigmatizing and labeling.

The exhibition was held at Asukastalo Mylläri Aulagalleria from 1st until 26th of February. This public space is used by Myllypuro inhabitants in regular basis and the art exhibitions change every month. There were altogether 15 paintings on display. I left a comment book, in order to receive opinions and thoughts about the painting and the exhibition.

The exhibition received 20 initials and the comments such as,

"Excellent work. Leave space for imagination and interpretation of a viewer".

Some of the viewers noticed the usage of colour and shapes,

"Fine use of colour at the paintings. At number 6 I saw a man laying comfortably inside a triangle".

However there were also critical comments such as,

"Quite awful crap. Why someone would like to have some of these "paintings" on their walls unless it is a messy speck of your own child".

The comments and feedbacks from the viewers, not only described the paintings, but also functions as mirroring own values and beliefs of the viewers. Ledwith (2005, 67) stresses that the link of community work and stories of the people as a foundation of action and reflection. Therefore the exhibition functioned as a tool for empowerment of the community of Sanervakoti reaching out to the local area of Myllypuro. The inhabitants of Myllypuro reacted to the exhibition by giving critical and analytical responses.

8. UNSTRUCTURED INTERVIEWS OF STAFF MEMBERS

I interviewed three staff members from Sanervakoti, in order to receive aspects and backup information from various professionals for my product thesis regarding importance of stimulating activity, discovering the effects and challenges. As the stimulating activity have been rapidly increased, I found that it is important to elicit the opinions of the staff members who are in direct contact with the residents in daily basis. The interviewed staff members represented all professional fields which are nurse, practical nurse and social instructor. The work experience at Sanervakoti varied from one and half to seven years. The interviews took place at Sanervakoti during October 2015. I have translated the interviews from Finnish to English myself.

8.1 Objectives for the stimulating activity at Sanervakoti

One of the objectives is that the stimulating activity function as goal-oriented approach which arises from element of functional and social rehabilitation. Many of the residents require assistance in any action they are about to make and they have very little initiatives of themselves. This decreased functional capacity influence their motivation to be active and has direct influence on their mindset as well. However, when the residents participate to communal activity, they at the same time, maintain their functional and social capacity.

A nurse from Sanervakoti explained that the increased significance for stimulating activity is apparent, because when the functional capacity of the individuals decrease, stimulating activity functions as motivator them to take part into social occasions. Stimulating activity has an immense meaning for increase well-being in everyday life. However if they have not selected the activity themselves, they might experience feelings of deficient.

The social instructor explained that if the activity is not person-centered it could cause stress that they are not capable to perform the actions. Stimulating activity as itself should serve the needs of the individual and increase functional and social capacity.

According to the social instructor, the activity should be something that they can select themselves and be able to "shine" and through that receive empowerment. Wegerer (2014) explained the benefits of stimulating activity, as it will maintain emotional connection with others, promote self-expression, decrease anxiety and make the patients with Alzheimer feel more connected with life. The stimulating activity should make the residents happy and focus on the wishes of the participants.

8.2 The effects of participation for stimulating activity for the resident

There are several domains that effect to the quality of life for people with Alzheimer and dementia.

"The challenges are in social interactions, awareness of self, feelings and mood, enjoyment of activities and responding to surroundings". (Rabins, Kasper, Kleinman, Black, & Patrick 2000, 37)

From experiences of the staff members, regarding to the residents thought and action, their activity level arises during the stimulating activity. The psychological influence is manifested by their behavior. They become into a better mood and behave much calmer when interacting with others.

Many of them look forward to the next stimulating activity, especially the singing afternoon, which has been functioning regularly. Although they find enjoyment in baking and painting, because of its functional nature.

For male residents, it is important to do activities in male company such as bowling. It can also bring out new hidden talents. Some inhabitants benefit from stimulating activity a lot. When they are interacting with other participants, they tend to gravitate into a familiar place and choose gathering with people they already know, someone from the same department. During stimulating activity, which is facilitated, they receive support for action and social reflection. Some of the residents require a lot support regarding social participation. Even though, if a resident would not be active in a group, being just present uplifts the mood and bring variety to everyday life.

Based on my observations at the stimulating activity, I paid attention especially for the residents mood during the activity. It was obvious, that only being part of the group, even if some of the residents did not participate, made them feel connected to the community and I could witness a sense of comfort and ease among the residents.

Stimulating activity functions as a medicine free tool in controlling symptoms from behavior problems. The activity can begin in small occasions such as having a conversation with the resident. The main purpose is to give individual time and attention. Social work with people with Alzheimer and dementia is to increase quality of life, despite of the problems. A person-centered plan with thorough information about the resident will help the staff members to find suitable and pleasant activity for the resident that would increase the quality of life (Milner, O`Byrne, 2009, 237).

To motivate the residents to take part into stimulating activity can be challenging. Although, it begins with the positive attitude of the staff members. Social instructor explained that before there was *Meno-maanantai* and *Toiminta-torstai* (both refers to action), where all who wanted could participate.

According to her interview it appeared that when it did not happen every day, the staff members were enthusiastic to motivate residents to participate. Some of the residents participate in everything with positive mood, although some residents found the new situations scary.

”They should at least come and look if they would like it and not decide immediately that they do not like it anyway, without even getting familiarized first” (Social instructor).

It seems that when residents recognize a familiar staff member, it motivates and encourages them to participate. Another way to motivate residents to take part into stimulating activity, is to include them already into planning process and content of the activities and clubs. Practical nurse suggested that a little gift (coffee, chocolate) can also function as a motivator to participate into stimulating activity. In conclusion, the staff members should present the stimulating activity as invigorating and natural activity for the resident.

8.3 Social inclusion

Regarding social inclusion, residents are directed to communal premises, rather than stay in their own rooms. The residents are also encouraged to be initiative themselves. The social mobility and cohesion to the community is maintained through everyday life actions. Dining together with other residents support sense of belonging in the community. Special communal events such as grilling in the yard takes place occasionally in the summertime.

The residents can even help each other together with supervisor. Part of the residents participate in everyday tasks, wiping the tables, taking out the trash and taking care of the laundry and so on. The behavior of the personnel effect how they are able to keep them at the shared communal space. It is challenging with the resident, who does not talk or does not want to talk. However to talk normally and to be present and recognizing their needs are important.

Stevenson (2016) explained at the article Dealing with Dementia Behavior Problems that aggressive use of voice can trigger feelings of fear and confusion for the resident. Especially with people of dementia and Alzheimer, there is no need to increase frustration and embarrassment. In the community, when there is time, the aim is to sit down and play board games, puzzles and cards together with those who enjoy it.

The residents also go out regularly with a supervisor, or in a small group. Stimulating activities support community spirit and social capability. At Sanervakoti 4th floor, there are students who live there as well as will bring their potential and effort by working 20-30 hours per month with the inhabitants. The residents also work a lot with their own representative supervisor. The core aspect that a personnel brought out is that the supervisor also should have a skill to inspire the community where they work. That would create a sense of unity for staff members, which would effect to the residents as well.

The social instructor saw a relevant aspect, when we were discussing about my role at Sanervakoti as a student. She pointed out that the supervisors should be more receptive towards the students and include them to the work community. As I felt most of the times, not be part of the work community. Martin (2003, 15) explained as follows:

“Leaders in all areas of service provision can influence the experience of both staff and service users and therefore can make a profound impression on how people feel about themselves, their experience and their well-being”.

Martin (2003, 14) also discussed about health and social care organizations, that there is a nature for multilayered hierarchies which creates a gap between different professionals. In my opinion, practicing hierarchies creates competitive atmosphere which causes stress and overall discomfort. The result can be seen in a sick leave absents of the staff members.

8.4 Values, communication and a meaningful life

According to the personnel of Sanervakoti, the core value for dignified life is respect one another, so that life is content. It was highlighted that if a person is ill or old, they crave feelings to be needed and important. Everyone deserves to be treated with dignity. Value stands for respecting the people with or without history of substance abuse, because everyone is worthy. When a person's basic needs (home, food and safety) are fulfilled, increases person's social and spiritual needs as well as self-expression.

At the intense assisted accommodation for people with memory illnesses it is necessary to live a steady lifestyle. In this kind of unit, changes should not happen too fast. Flexibility and ability to make logical decisions are important qualities for staff members. The ability to make logical decisions is valuable with people with memory illnesses because they might express their needs differently of what they actually mean.

For people with dementia and Alzheimer a common symptom for is depression, which arises e.g. from feelings of frustration of being unaware of communication difficulties (Cox, 2007, 40). Therefore staff members have to control their own temper. Practical nurse added communication skills to the values. She stated as follows:

” Communication with people with memory illnesses, it is especially important to speak calmly and slowly. It is not meaningful to cause confusion and discomfort” (Practical nurse).

It is necessary to maintain resident's social affairs. Some of the residents do not have relatives, or a relationship towards relatives has ended, therefore supervisor becomes as a family member for those individuals. The responsibility of supervisor is to create a care relationship, that together they can plan the content for the resident's life and through that find meaning for life. Small things matter. The personnel need to look from his/her own perspective and be very empathic.

According to the Lead instructor, at the intense assisted accommodation for the people with memory illnesses, resident is not a target for care, he/she is instead of active, participator in their own life.

9. OBSERVATIONS FROM STIMULATING ACTIVITY

9.1 Observation of singing afternoon

Thu 1st Oct, at 13:30-14.30

Present: 4 women, 4 men

Sanervakoti has a contract with music teacher from Workers Institute, whose purpose is to lead singing afternoon. For many of the inhabitants it is very empowering, and that is perhaps the reason why it has been so successful. I collected percussion instruments, which could be played along while singing. The teacher began the session by playing familiar songs from cd. She asked if people knew the songs and someone always did. Then she began to play the piano and sang traditional Finnish songs she had selected in advance.

All the words from the songs are compiled to a leaflet in large font, so that everyone can follow the songs, even though they might not sing by themselves. The participants were visibly excited and enjoyed the activity. Everyone had a percussion and played those with excitement. Instruments also gave a chance for those who did not want to sing a possibility to participate and include themselves to the common activity.

Suddenly, a female participant started to dance and took a male participant from hands to join her. They were dancing palms held to one other and danced according to the rhythm of the music for few minutes. Once they finished the male inhabitant moved into tears and was touched by the emotions what the touch and dancing together manifested.

9.2 Observation of coloring pictures

Tue 29th Sept, at 15:40-16:20

Present: 3 women, 1 man

The focus was very intense when observing inhabitants in colouring book task. Everyone were very concentrated on colouring pictures with special details that took some time to complete.

Practical nurse was at the same time asking questions such as: What is your favourite colour? When have you coloured a picture the last time? One inhabitant colors with excitement and then have pauses just to look at the picture. The pauses lasted several minutes before he continued. Everyone felt uplifted after the session and wanted to do it again another time.

10. ANALYSIS OF THE OBSERVATIONS

The purpose of the observations at the stimulating activity is to report what happens when the participants are focusing on creative activity. The participation of the observed stimulating activity varied from 3 to 20 residents. As Block (2008, 95) explained about the power of a small group, is that the participants become more authentic and natural in a small group. As I noticed at several sessions, some inhabitants arrived to stimulating activity without participating. They were very happy just to be there together, being included into the community.

As Johnson, Walmsley and Wolfe (2010, 59) argue;

“If one is excluded from participation, then one is not considered centrally in the principles of justice that govern the society”.

On the other observations such as singing, Peltokangas and Rantala (2009, 33), explained at their thesis about the effects of singing as follows;

“Music has ability to awaken inner world of experiences and has powerful effect on emotions. “

Calm, relaxing environment was very important starting point when we began the painting sessions. This way they felt comfortable and secure. I noticed that correct rhythm in leading the activities was the key to maintain concentration. It was vital to have sensitivity to see when they needed more time or when they needed to change a task. According to Block (2008, 127) everyone is a creator of the community and can affect how it can appear. It is dependent on the determination of self.

At Sanervakoti the extra challenge arrived in general to work with people of memory illnesses, where I did not have any previous experience. Although when I treated everyone with respect, the fact, that they were diagnosed with dementia, did not play the significant role.

11. PROFESSIONAL DEVELOPMENT

My personal process of the thesis production was very intense. During my Community, Empowerment and Participation placement period in September and November 2015, I observed the residents and staff members, facilitated stimulating activity, did plenty of self-reflection and received experiences how every day life is functioning at care unit for people with dementia. The facilitation of the stimulating activity during the production for Path of Stories, forced me to learn fast how to communicate with the residents.

I noticed that it was difficult to remember, that most of the residents were not capable of maintaining a normal discussion and often found myself confused what to say to them. The intensity manifested during the last week of my

placement. The paintings for the exhibition were produced during one week including printing, laminating and production of the marketing material.

The original plan for the space of the exhibition was to hang up the paintings outside the Sanervakoti front yard. However, this idea had to change because of the circumstances regarding weather and accessibility for inhabitants of Myllypuro.

I chose the public premises of Community House Mylläri, which has a lounge gallery, in the middle of Myllypuro shopping center. This choice was much better, because the paintings were safe and at clean space and the location was convenient any one to visit. Community House Mylläri and Helsinki Local Work Unit are strongly involved with Tarinoiden Myllypuro project and Path of Stories, therefore to hold the exhibition at their premises, were appropriate.

As a student in a new working environment, it was very difficult to become part of the community and produce material for my thesis when most of the time I was ignored. I did not receive support or guidance from the staff members either. Despite of the communication problems, this thesis process as a whole, gave me a new experience to work with vulnerable group of people and be able to promote their social justice through art, which is the purpose why I chose to study the social services. The thesis process have also strengthened my professional identity as a social instructor and also it developed my skills for management of the production from the beginning to the end. It was vital to experience and witness how the methods were applied into practice, as well as see the empowerment of the residents. In order to work in the social field, it is necessary to be able to reflect own values and attitudes and create a strong self to cope and solve problems of the working environment. The values of the organization should be internalized among the staff members, so that the values become reality.

12. CONCLUSION

Having pleasant and stimulating activity during the day is a basic need for human beings. It revitalizes, maintains functional capacity and it has psychological effects by bringing positive outlook to life. To fully recognise the needs of the individual requires time. Especially with people with dementia at Sanervakoti, it takes time to familiarise with people's abilities and interests.

The stimulating activity can have significant meaning in care organizations for people with memory illnesses. In particular it is challenging to work with people with dementia, whose viewpoint of time varies, or it does not exist. The frustration level increases, which causes aggression and restlessness that can provoke other inhabitants. However, stimulating activity can lessen the frustration, make the residents feel worthy, meaningful and uplift their mood. With regard creative method such as painting Peltokangas and Rantala (2009, 34) argue in their research;

“Painting can be a gateway to memories and functions as a bridge to internal and external reality”.

Especially with people with memory illnesses, the non-verbal communication becomes important. It is authentic self-expression and dialogue with the inner world. And that is what empowering at its core is about. The findings of this thesis are the collection of observations, facilitation and interviews. According to the interviews of the staff members, participation in stimulating and communal activity has benefits for functional, social and psychological capacity. However it is necessary to pay attention to the wishes of the residents, in order to truly benefit from the stimulating activity.

By including the residents to the planning, it also promotes social justice. Therefore encouraging to take part, should not be a burden for the staff, it should be seen as joyous action for encouraging resident to lift up their spirits.

The supervisor has a vital role in creating an inspiring community spirit, motivating and encouraging the staff members, especially practical nurses, who are mainly performing their daily routines. The communication among staff members should be based on respect and equality as the mood and behavior of the staff members have direct impact on the community and residents. In my opinion, it appears that they are enthusiastic to develop the content towards more holistic, person-centred approach and well-being of the inhabitants at Sanervakoti.

However, they seem to have challenges regarding communication with the staff members. I paid attention to the tone of the voice, when they were discussing with each other and to me. The demanding nature of the work with people with memory illnesses can increase pressure and stress. As Siitonen (1999, 89) emphasized in his research, empowering the work community by promoting appreciation and supporting equal social structures, lessens the pressure on its members.

Referring to Siitonen (1999, 97), empowerment is connected to the environment which enables aspects such as freedom of choice, safety, positive atmosphere and appreciation to manifest well-being of the organization.

The essence is to treat not only the residents, but the co-workers as well with respect which leads directly to development of community spirit. Respectful behavior promotes cohesion, safety, positive atmosphere and home-like living, which are the core values of Sanervakoti.

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APPENDIX 1. WEEKLY PROGRAMME FOR STIMULATING ACTIVITY

SANERVAKODIN KLUBITOIMINTA

PARILLINEN VIIKKO KLO 13.30	PARITON VIIKKO KLO 13.30
<p>PELIKLUBI</p> <p>Lauta- ja korttipelit.</p>	<p>MUSIIKKIKLUBI</p> <p>Levyraati, lauluhetket tai musiikin kuuntelu eri teemojen mukaan.</p>
<p>ELOKUVAKLUBI</p> <p>Teemapäiviä ja pop cornia: Toimintaleffa, kotimainen elokuva, romanttinen komedia...</p>	<p>KUVATAIDE- JA ASKARTELUKLUBI</p> <p>Maalaaminen/piirtäminen ja askartelu eri teemojen mukaan.</p>
<p>OPISKELIJOIDEN ILTAKLUBI KLO 18</p>	<p>OPISKELIJOIDEN ILTAKLUBI KLO 18</p>
<p>MUSIIKKIKLUBI</p> <p>Kansalaisopiston kuoro</p>	<p>KOKKIKLUBI</p> <p>Muffinssit, teelevät, pulla, sämpylät, pannari, letunpaisto...</p>
<p>PELIKLUBI</p> <p>Toimintapelit ulkona tai sisällä: Kroketti, petankki, mölkky, keilapeli, hernepussin/pallonheitto, tietovisat, bingo...</p>	<p>LIIKUNTAKLUBI</p> <p>Ulkoilua, tuolijumppaa, musiikkiliikuntaa ja tanssit kerran kuukaudessa.</p>

APPENDIX 2.

Interview questions for Sanervakoti staff members.

1. What is your profession?
2. How long have you been working at Sanervakoti?
3. How essential do you evaluate the stimulating activity for the inhabitants?
4. In your opinion, how do you see the impacts of stimulating activity for the inhabitant? (thought and action, interaction with other inhabitants and staff members).
5. How the inhabitants should be motivated to take part into stimulating activity?
6. In Sanervakoti, how does the social mobility and social inclusion is maintained?
7. In your opinion, what are the core values of a good life?
8. How good and dignified life should manifest at the intense assisted accommodation unit of people with memory illnesses?

APPENDIX 3.

Liite 1

Suostumus tutkimukseen osallistumisesta

Sanna Luoman (DIAK AMK, Degree of Social Services) opinnäytetyö. Osallistava tutkimus on Sanerva-kodin viriketoiminnasta ajalta 21.9.-27.11.2015. Havainnoinnin lisäksi tarvitsen haastattelumateriaalia henkilökunnalta. Tutkimus julkaistaan Helsingin Diakonissalaitoksen internet sivuilla, sekä Theseus tietokannassa.

Minulle on selvitetty yllä mainitun tutkimuksen tarkoitus ja tutkimuksessa käytettävät tutkimusmenetelmät. Olen tietoinen siitä, että tutkimukseen osallistuminen on vapaaehtoista. Olen myös tietoinen siitä, että tutkimukseen osallistuminen ei aiheuta minulle minkäänlaisia kustannuksia, henkilöllisyyteni jää vain tutkijan tietoon, minua koskevaa aineistoa käytetään vain kyseiseen tutkimukseen ja aineisto hävitetään tutkimuksen valmistuttua.

Suostun siihen, että minua haastatellaan ja haastattelussa antamiani tietoja käytetään kyseisen tutkimuksen tarpeisiin. Voin halutessani keskeyttää tutkimukseen osallistumisen milloin tahansa ilman, että minun täytyy perustella keskeyttämistäni tai että se vaikuttaa hoitooni tai asiakassuhteeseeni/työsuhteeseeni.

Päiväys

Tutkittavan allekirjoitus ja nimenselvennys

APPENDIX 4.

Lehdistötiedote Tammikuu 2016

Sanervakoti esittäytyy - TARINOIDEN POLKU

Tarinoiden Polku on näyttely Sanerva-kodin kuvataideryhmän tuotoksista lokakuulta 2015. Sanerva-koti on on pitkäaikais- ja muistisairaiden asumisyksikkö Myllypurossa. Sanerva-kodissa korostetaan viriketoiminnan merkitystä elämänlaatua parantavana elementtinä. Näyttelyssä on yhteensä 15 maalausta, mitä ei ole nimetty etukäteen. Katsoja voi halutessaan jättää kommentteja teoksista, miten ne koskettivat ja mitä katsoja niissä näkee.

Tarinoiden Polku on osa Tarinoiden Myllypuro hanketta, mikä käynnistyi keväällä 2015. Hankkeen tavoitteena on tuoda esille myllypurolaisten tarinoita elämästään ja kokemuksistaan Myllypurosta asuinalueena.

Tarinoiden Polku-näyttely on esillä Asukastalo Myllärissä, Kiviparantie 2 J (keskellä Myllypuron ostaria) 1.2 - 26.2.2016.

Tervetuloa!

Lisätietoja:

Sanna Luoma / Diakonia AMK
DSS

Sanna.Luoma@student.diak.fi



APPENDIX 5.

Tarinoiden Polku juliste

TARINOIDEN POLKU

Sanervakodin asukkaiden maalauksia

Lokakuulta 2015



Asukastalo Myllärissä

1.2 - 26.2.2016

Kiviparintie 2 J (keskellä Myllypuron ostaria)

 **HELSINGIN
DIAKONISSALAITOS**

 **Helsingin kaupunki**
Sosiaali- ja terveystieteiden
virasto