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KEY ELEMENTS OF PERSON CENTERED ACTIVITIES FOR PEOPLE WITH DEMENTIA IN LONG TERM CARE – SUOMI KOTI

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The purpose of this study was to find out what kind of activities residents at a Finnish nursing home in Toronto like and what kind of activities they want to participate in. Thesis looked in to what kind of activities are stimulating and activate people with dementia in long term care. Study is showing perspective of the volunteers and care staff on the activities offered as well as input on the training and support offered through Suomi-Koti for their activities. This thesis is a qualitative, theme study with semi-structured interviews with residents, volunteers and nursing staff.

Interviews were administered January and February 2018 with 12 residents, 10 volunteers and 8 care staff members. All but one resident interviews were in Finnish, rest of the interviews were in English.

The findings show key elements of person- centred activities are that residents enjoy the activities provided, the activities are based on the residents' wishes, and the activities are both creative and stimulating. Resident should feel they are included in a group and their lives still matter while living in a nursing home. Volunteers and care staff leading the activities should know the residents well enough to engage and adjust the activities based on residents wishes and to be there for the residents. Further finding for Suomi-Koti is that more volunteers doing one-on-one activities with residents are needed.

KEYWORDS: Dementia, activating methods, stimulating methods, creativity, person-centred activities

[Avainsanat]

OPINNÄYTETYÖ (AMK) | TIIVISTELMÄ

TURUN AMMATTIKORKEAKOULU

Pia DeMartini

IHMISLÄHTÖISEN TOIMINNANOHJAUKSEN AVAIN ELEMENTTEJÄ MUISTISAIRAIDEN PITKÄAIKAISHOIDOSSA - SUOMI KOTI

Tutkimuksen tarkoituksena oli selvittää, millaisesta toiminnasta Torontolaisen suomalaisen hoivakodin asukkaat pitävät ja millaiseen toimintaan he haluavat osallistua. Opinnäytetyössä tarkasteltiin, millaiset toiminnot stimuloivat ja aktivoivat muistisairaita pitkäaikaishoidossa. Tutkimuksessa kerrotaan vapaaehtoisten ja henkilökunnan näkemyksistä tarjolla olevista toiminnoista sekä heidän mielipiteitään Suomi-Kodin tarjoamasta koulutuksesta ja tuesta heidän toiminnalleen. Tämä tutkimus oli luonteeltaan laadullinen ja tiedonkeruu tapahtui teemahaastatteluiden avulla.

Haastattelut tehtiin tammikuussa ja helmikuussa 2018, johon osallistui 12 asukasta, 10 vapaaehtoista ja 8 hoitohenkilökunnan jäsentä. Kaikkien asukkaiden paitsi yhden asukkaan haastattelut olivat suomeksi, henkilökunnan ja vapaaehtoisten haastattelut tehtiin englanniksi.

Tutkimuksen tulokset osoittavat, että ihmislähtöisen toiminnan keskeisiä tekijöitä ovat, että asukkaat nauttivat tarjotusta toiminnasta, toiminta perustuu asukkaiden toiveisiin ja toiminnot ovat luovia ja stimuloivia. Asukkaiden tulisi tuntea, että he kuuluvat johonkin ryhmään, ja heidän elämänsä on vielä tärkeää hoivahodissa asuessa. Vapaaehtoisten ja hoitohenkilökunnan tulisi tuntea asukkaat riittävän hyvin, jotta he voivat sitoutua ja muunnella toimintaa asukkaiden toiveiden mukaisesti ja olla asukkaille läsnä. Tulokset osoittivat myös, että Suomi-Koti tarvitsee enemmän vapaaehtoisia tekemään kahdenkeskistä toimintaa asukkaiden kanssa.

ASIASANAT:

Muistisairaus, aktivoivat menetelmät, stimuloivat menetelmät, luovuus, ihmislähtöinen toiminta

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List of Abbreviations (OR) Symbols

ASC	Alzheimer Society of Canada
GPA	The Gentle Persuasive Approach
LHIN	Local Health Integration Network
MDA	Montessori for Dementia and Aging
MTC	Music therapeutic caregiving
OMA	Opening Minds through Art
PSW	Personal support worker
RN	Registered nurse

1 INTRODUCTION

The two common themes of this thesis around activities for people with dementia are: person centered care and taking a creative approach to activities. Activities enable people with dementia to express themselves and communicate things that would be difficult for them to express in another way. Examples of basic tasks for daily living caring for people with dementia are personal care and hygiene, eating and mobility. Activities can also provide a good change of pace from the repetitive tasks that are a part of daily life. This thesis looks into what kind of activities residents like and is Suomi-Koti currently providing those kinds of activities. Study also asks volunteers and care staff's opinion about activities, how they see activities are affecting residents and if something can be done differently at Suomi-Koti when providing activities. Results of this study can give Suomi-Koti support and ideas when adding new activities and recruiting volunteers.

People with dementia should be encouraged to give their preferences. Alzheimer's Disease International's world report (2016) lists four main recommendations for care of people with dementia: systematisation of care processes, managing complexity of mental and physical health, need for more research and more coverage of dementia care. (Alzheimer's Disease International 2017.)

Worldwide there were estimated 46.8 million people living with dementia in 2015 and number is expected to reach 131.5 million in 2050. There are almost 10 million new cases every year. Care for people with dementia should be continuous, holistic and person-centred and treating the whole person according to their preferences and values. Care also should be integrated across all levels of care provision and health and social care providers. People with dementia are more likely to be admitted to a hospital than people of same age and the process of hospital care is more complicated for people with dementia and requires more nursing resources than others. Healthcare staff need greater understanding of the challenges for the person with dementia and the mental health liaison service should be considered in hospitals. A good palliative and end-of-life care is often lacking for people with dementia and more clarity is needed on the policy for them. (Alzheimer's Disease International 2017.)

In Canada there are 25,000 new cases of dementia diagnosed every year and about 1.1 million Canadians are affected directly or indirectly by the disease (Alzheimer Society of Canada 2016). In Ontario the Ministry of Health and Long-Term Care inspects, regulates

and sets out fees for all its 627 long term care homes with over 78,000 residents. (Government of Ontario.)

Alzheimer Society of Canada (ASC) focuses on a person-centred approach and in 2012 ASC embarked a " Culture Change Initiative" in Long Term Care. The aim for it was to improve the experience on long term care for people with dementia and their families, and work with others to provide useful strategies, tips and tools that can help put person-centred care into practice. In 2012, ASC conducted an exploratory qualitative research study in six long-term homes across Canada to understand how person-centred care is put into practice. Through this research, ASC learned about seven common key elements to begin and sustain a culture change to provide person-centred care called PC P.E.A.R.L.S.™, under the following headings: person and family engagement, care, processes, environment, activity and recreation, leadership and staffing. If nursing home puts these key elements in action, the home can become a home like model where staff, residents and families work together as a team. (Alzheimer Society of Canada 2017.)

Long-term care homes must work within regulations and legislations to meet the needs of people with dementia. Compliance with regulations and legislation imposes rigorous standards of care and it has historically focused on "tasks" rather than a person-centred approach. This makes it harder to run long-term care homes with a person-centered approach. (Alzheimer Society of Canada 2017.)

Every long-term care home in Ontario is required to prepare a Quality Improvement Plan each year. Homes can pick topics to include based on a review of what their home needs to work on most and discussions with residents, family members, and staff members. Last year one common topic at long term care homes was how to improve the experience for residents living in long term care. (Health Quality Ontario 2017.)

2 LITERATURE REVIEW

Memory is our ability to store, retain and encode information and past experiences in the human brain. Memory gives us the capability to learn and adapt from previous experiences and build relationships. Memory is the store of things learned and retained from our life and experiences. To understand function of the memory it is to distinguish between sensory memory, short-term memory and long-term memory. Sensory memory brings brain awareness through the senses. It can still be divided into icon, echo and touch memory depending on what senses are stored in the brain area. Sort-term (working) memory is part of consciousness and has the ability to remember and process information at the same time. Sort-term memory keeps things in mind for just a few seconds. Long-term memory is divided into the semantic memory of facts and the incident or episodic memory containing stories and experiences. Long-term memory also has a skill memory that stores learned skills such as driving a bike. Long-term memory is like an unlimited warehouse. So, we can endlessly store information and experiences that can be remembered throughout our lives, although it just might become increasingly difficult to access certain items from memory. (Alzheimer Society of Finland 2018.)

Harmel and Orrell's (2008) study explored concepts of meaningful activity, as thought by older people with dementia living in care homes in London, staff and family carers. The study used three separate focus groups from three different care homes. Content analysis let to emerge four main activity themes from residents focus group; reminiscing, family and social, music and individual, which were to be particularly meaningful to people with dementia. Two other themes emerged; "lack of meaningful activity" and "what makes activities meaningful". For staff and family carers reminiscing and family and social and music were important to some degree. Residents liked meaningful activities that addressed their social and psychosocial need and the experiences of an activity was more meaningful than any specific type of activity. Staff and family carers thought activities that were more physical as more meaningful. The study showed that activities need improvement on how providing activities for people with dementia. (Harmel & Orrell 2008, 549-556.)

2.1 Dementia

Dementia is a term for a set of symptoms that are caused by different disorders affecting the brain. Dementia is progressive, and the symptoms will gradually get worse as more

brain cells become damaged and die. The most common form of dementia is Alzheimer's disease. Other common forms of dementia are vascular dementia, frontotemporal dementia, Lewy body dementia and mixed dementia. (Alzheimer Society of Canada 2017.)

2.1.1 Alzheimer's disease

Alzheimer's disease was identified by Dr. Alois Alzheimer in 1906. The disease causes symptoms of dementia like memory loss, behavioral, emotions, difficulty doing daily activities. These symptoms are irreversible, and any loss of abilities cannot be reversed. Symptoms of Alzheimer's disease are caused by the destruction and death of nerve cells in the brain. (Alzheimer Society of Canada 2017.)

2.1.2 Vascular dementia

Vascular dementia occurs when the brain's blood supply is damaged or blocked, causing brain cells to be deprived of oxygen and die. A network of vessels called the vascular system supplies the brain with oxygen, allowing the brain function. If the vessels supplying the brain are blocked, bleeding or diseased, blood is prevented from reaching the brain. When there is no oxygen and nutrients, the affected cells in the brain die. This leads to stroke symptoms that might cause vascular dementia. (Alzheimer Society of Canada 2017.)

2.1.3 Frontotemporal dementia

The frontotemporal dementia often occurs at a younger age than Alzheimer's disease. This type of dementia resembles Alzheimer's disease in that it also involves the progressive degeneration of brain cells, that can no longer be reversed. People with frontotemporal dementia have symptoms like sudden onset of memory loss, difficulties with speech and movement, behavioural changes. Frontotemporal dementia is a group of rare disorders that mostly affect the frontal and temporal lobes of the brain. These areas are generally associated with behaviour and personality. In frontotemporal dementia, the changes in the brain affects the person's ability to function. (Alzheimer Society of Canada 2017.)

2.1.4 Lewy body dementia

Lewy body dementia occurs because of abnormal deposits of a protein called alpha-synuclein inside the brain's nerve cells. These deposits are called "Lewy bodies", after

the scientist who first described them. The deposits interrupt the brain's messages. Lewy body dementia affects the areas of the brain that involve movement and thinking. (Alzheimer Society of Canada 2017.)

2.1.5 Mixed dementia

Mixed dementia has similar characteristics of both Alzheimer's disease and vascular dementia. It is a condition where changes representing more than one type of dementia occur same time in the brain. People with mixed dementia are usually diagnosed with single type of dementia. Mixed dementia is diagnosed after a brain autopsy. (Alzheimer Society of Canada 2017.)

2.2 Person-centred care

In the 1990's, there was a shift from medically oriented focused care to a more person centered supportive and individualized approach, with care focusing on the whole person. Professor Tom Kitwood was one of the first researchers studying person centered care. Kitwood was an advocate for people with dementia. He believed that medical terms led to people with dementia being seen as objects with no identity or personhood. Person-centred care sees the impact of social environment and quality of our interaction with people who have dementia and not just the disease process itself (Lee & Adams 2011, 2.)

Nursing's *Best Practice Guideline* of Ontario (2015) provides resources for evidence-based nursing practice with enhancing person- and family centred care. Guidelines are a good guide for developing policies, procedures, protocols, educational programs, assessment and documentations. Evidence-based approach with the idea the person been the centre of health will improve the satisfaction of care and services provided within the health system. Person- centred care focuses on the whole person as a unique individual and not just on their illness or disease. Using this kind of care health care providers and other staff will understand the person's life story and family. Communication and shared decision making is important as well as being flexible and personalizing care routines. Staff's commitment to person-centred care establishes a therapeutic relationship with the person using verbal and non-verbal communication strategies to build a trusting, and respectful partnership. (Registered Nurses Association of Ontario 2015, 5-12.)

In Alzheimer Association of Finland's guide (2016) lists rights for people with dementia. Those rights among are: right to be heard as an adult person and to be heard, that their feelings and opinions are valued, right to be as an active participant, the right to be treated well based on empathy and understanding of dementia care, right to experience being a relevant part of their community and society, the right to live in a safe environment a meaningful everyday life, right to go outside regularly and right to an expert in their own life. (Alzheimer Association of Finland 2016.) Ontario's Long-Term Care Homes Act (2007) has same kind of *Residents' Bill of Rights*, which Suomi-Koti follows. Government of Ontario believes in resident-centred care and the Long-term Care Act states:

"The fundamental principle to be applied in the interpretation of this Act and anything required or permitted under this Act is that a long-term care home is primarily the home of its residents and is to be operated so that it is a place where they may live with dignity and in security, safety and comfort and have their physical, psychological, social, spiritual and cultural needs adequately met. 2007, c. 8, s. 1" (Government of Ontario.)

2.2.1 Kitwood's personhood

The term personhood can be found in three main types of discourse: those of ethics, those of transcendence, and those of social psychology. In the main ethical discourses in Western philosophy, the idea is that each person has absolute value. We have an obligation to treat each other with respect. Transcendence is the idea that being-in-self is sacred, and life is to be revered. In social psychology personhood has a flexible and varied use, like self-esteem and individual in a social group. Having dementia does not mean a loss of personhood. (Kitwood 1997, 8-13.)

The main psychological needs of people with dementia are comfort, identity, occupation, inclusion, attachment and love (Kitwood 1997, 82-83).

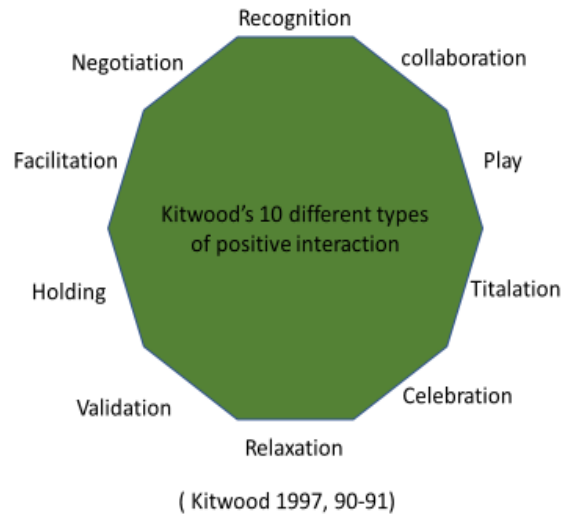


Figure 1. Kitwood's 10 different types of positive interaction (Kitwood 1997, 90-91).

Often the focus of caring for people with dementia is on the physical needs and there is little time for psychological needs. When people with dementia are seen as only "behaving", an essential feature of their personhood is lost. In dementia care, different types of interaction merge into one another. Those who work with people with dementia should remember to "be present" and let go of the idea of *doing* and embrace *being*. (Kitwood 1997: 89-93, 119.)

2.2.2 Montessori approach for dementia

Montessori for Dementia and Aging (MDA) is an innovative approach to dementia care that can be adopted for groups or individuals as a philosophy of care. The goal of the Montessori program is to support people living with dementia by creating a prepared environment, filled with memory supports, that enables individuals to care for themselves. The focus of Montessori approach is on 'doing' with activities being based on individual needs, interests, strength and abilities. This focus leads to activities that are meaningful to the person and enrich their lives. Montessori Methods for Dementia focus on supporting both the person and the environment which is adapted to support memory loss and independence. Since memory is impaired, remembering information for any length of time is a challenge, and Montessori Methods for Dementia focuses on

putting information into the environment like cue cards and in memory books and working with preserved abilities like reading. (Association Montessori Internationale 2018.)

Van der Ploeg et al. (2013) used randomized crossover trial in nine nursing homes in Melbourne Australia ($n = 44$) to study the effects of personalized one-on-one activities using Montessori principles. These were compared with non-personalized activity. Twelve residents that participated in the study, who had immigrated to Australia, had lost their fluency in English. Each participant had physically non-aggressive agitated behavior that occurred at least several times a day outside the nursing intervention. Participants were observed 30 minutes before, during, and after the sessions. Study period lasted four weeks, where participants did two weeks of Montessori and then switched to control session activity for two weeks as well. During both control sessions and Montessori agitation scores were nearly halved. At Montessori sessions there were more positive effects, more constructive engagement, and less negative engagement than at control sessions. Montessori interaction was also more effective for participants who had lost fluency in English in reducing levels of agitation. (van der Ploeg et al. 2013.)

2.2.3 Daily living with dementia

Heggestad's et al. (2015) study purpose was to gain more knowledge about how people with dementia, and their family members, experience how dignity is being maintained or harmed in a nursing home. Seven family members from two nursing homes in Norway were interviewed and residents were observed by authors participating as an assistant in the daily life. Family members wanted insurance that residents were allowed to live their life as equal human beings and that relational needs were met with person-centred care. Family members felt lack of resources and task-oriented care was a threat to that. Observations of the residents confirmed that. Giving person-centred care, combined with a relational focus is a good way of maintaining the dignity of people with dementia in nursing homes. (Heggestad et al. 2015, 828-829; 832-834.)

Person with dementia and their ability to speak language learned in later life may be lost. Hanssen's (2015) study focused on factors that make communication and reciprocal understanding difficult when people with dementia and health personnel come from different cultural and linguistic backgrounds, and the consequences this might have on the quality of care. In the study 35 nurses in dementia care and 26 family members of people with dementia were interviewed in six geriatric facilities (one in Oslo Norway, one in Sami town in northern Norway and four in Tshwane, South Africa). Nurses had

different cultural and linguistic backgrounds than their patients. Patients often lost their knowledge of the majority language and nurses might not know patient's language and culture. Study showed that lack of linguistic skill of nurses was a problem. The majority of the interviewees, both family members and nurses, said language to be primary in dementia care. In spite of difficulties for common language the general opinion was that it was possible to communicate quite well with the patients. Sometimes nurses felt patient was uneasy, frustrated and frightened. Nurses physical presence and how they talked to the patient was important way to understand patients. Usually permanent staff could communicate with the patient better than other staff and students. Nurses who speak patient's language are valuable asset working with people with dementia. (Hanssen 2015, 1; 5-10.)

Case study by Ward et al. (2011) explored the friendship of people with early stage of dementia and beyond the benefits of relative's support network. Two case studies included "personal narrative on friendships" from one of the authors, a person living with dementia. Second care study was a "Friends for Life" peer support project (2010-2011). Evaluation was done by observing each peer support group, joint discussions with the members and interviews with the project staff. Members had different needs and they found various connections that supported them to continue going to the group meetings. It was important to share experiences of dementia and it was valuable to have a place of belonging. Staff said their job at the meetings was to support rather than lead them, which was a learning experience and leading the meeting still sometimes happened. Members referred to one another friends and change of people with early stage of dementia connecting with others in a similar position can be life-enhancing. Friendship narratives could support practitioners to recognize the social consequences of receiving a diagnosis and stigma it carries. (Ward et al. 2011, 288;291;296-298.)

Billington et al. study (2013) was to understand the influence that reading has on older people with dementia in different health care environments, identify staff perceptions of the effect that engagement in a reading group has on people with dementia and to investigate any changes in dementia symptoms of people participating in a reading group. Sixty-one older people with dementia and 20 staff members took part in the study. Results showed that the reading group appears to be a positive activity in all of the health care environments that took part in the study. Reading group activity appeared to produce a significant reduction in severity of dementia symptoms. Reading group allows

members to interact with each other in a meaningful way. (Billington et al.2013, 166-171.)

Higgins study (2014) wanted to understand the impact the faith has on lives on people with dementia. Ten residents with moderate to advanced dementia living in four care homes participated in the study. Semi-structured interviews were trying to understand what role religion played in participants lives and what way faith affected them in their current life. Three themes were found; (1) Faith is an integral part of participants identity, (2) participants relationship with God is central to their life, (3) Faith is reassuring and comforting to the participants and it connects their part with the future. Faith helps participants live their life now. Participants were highly religious. Higgins states, that keys to support religious needs of people with dementia is to have care home staff partner with the local faith communities and staff to know each resident's history and preferences with faith practices important to the resident. (Higgins 2014,324-325;334.)

2.3 Creative approach in activities

A lot of effort has been put to finding ways of better managing dementia, including art activities. Several researchers have found that creativity exists throughout a person's whole lifespan and people with dementia can still be creative and enjoy activities at long term care.

Creativity means something new and different in the context of dementia. It includes self-exploration as an individual and sharing creative expression through interaction with other people. People with dementia can enjoy meaningful and satisfying experiences through creativity, to the extent that their memory allows it (Gottlieb-Tanaka 2006, 43.)

Creativity can increase with the onset of dementia. Creativity can give hope to people with dementia because it offers meaningful communication and volunteers and nursing staff can focus on a person's strengths rather than their limitations. Because intellectual capacity with people with dementia may have diminished, they might be thrown back on emotion. Art can be a natural outlet for their reaction to the experiences they are dealing with. Sometimes people are locked insides themselves and the arts can provide a set of keys. Being creative is a good activity and a way of communicating with others and having existence. In these ways, art activities can be psychologically therapeutic. (Killick & Craig 2012, 19-21.)

Sauer et al. (2016) studied person-centered and intergenerational arts activity program called *Opening Minds through Art (OMA)* at three different long-term care places in Ohio USA. OMA is based on Kitwood's (1997) person-centered philosophy and strength-based psychology (Ronch, 2003). During 15-month period 38 OMA participant with moderate to advanced dementia participated 60 min weekly art-making session with trained student volunteer (trained in the OMA program philosophy and basics of dementia). Each week there were different activity aimed towards stimulating different senses and the curiosity of person with dementia. A subsample of 10 of these OMA participants also participated in traditional arts sessions and were observed biweekly. Study showed that participants demonstrated considerable well-being like engagement, social interest and pleasure with little or no ill-being during OMA. It suggests that OMA activities offer people with dementia a stimulating environment that enhances their well-being. The increased in social interest and pleasure was also partly because interactions with volunteers. Results show that OMA may offer better opportunities for engagement and pleasure than traditional arts and craft activities. (Sauer et al.2016, 898-907, Ronch 2003, 315-341.)

Fels and Astell (2011) studied conversational model of storytelling to the verbal reminiscences of older people with dementia. The study examined resilience of storytelling in the face of progressive cognitive loss and to explore the potential for storytelling to continue to fulfill a social function for people with dementia. Twenty-seven people with dementia from day care center and social work department care home participated in the study. Participants were shown six set of photographs of different annual events as Christmas, Easter and Birthdays. Each participant was seen individually. Participants were asked to discuss their memories of each event and were allowed to talk as long as they wanted. Reminiscing was free from expectations and there were no right or wrong answers. Sometimes photographs did not create any stories. Study identified 4 basic components relating to form and function by Langellier (1989), Labov & Waletzky (1967) which are (1) a story text, (2) the context and sociocultural setting, (3) the audience or listener contribution and (4) performance, ownership, and control of the story. Study suggests that people with dementia retain the 4 basic components, even when dementia is quite advanced, and storytelling can provide a conversational model for people with dementia. Family and formal caregivers are encouraged to engage people with dementia in conversations and prompt them to recall and recount personal narratives. Good storytelling requires listeners as well and listeners

has to understand the important role they have in the storytelling process. (Fels & Astell, 2011: 535-536, 540, Labov & Waletzky 1967, 12-14.)

Malmivaara and Kivelä (2015) has researched and developed a series of models that activate both brain and memory functions and develop the content of these models. Four person-centred service models were developed in the *Art and Culture-Keys for Better Brain Health* research development project. (Malmivaara & Kivelä 2015,29-31.) Models are:

The stage of Memories- The objectivity is to activate brain and memory functions with the help of old photographs and other visual material that were important to the participants.

What do I want to remember from my life? – The objectivity is to create illustrated stories of significant life experiences and memories by using participants childhood photographs and visual arts and same time activating brain and memory function.

Yellow Cottage and a Patch of Potato – The objectivity is to activate brain and memory functions by studying the architecture of the childhood home and environment with photographs, personal stories and visual arts.

Genius Body- The objectivity is to activate brain and memory functions with the help of creative movement and self-expression exercises by moving, observing, dancing, listening, meeting and encouraging the participants to discover something new and to do things differently. (Malmivaara & Kivelä 2015: 50,92,130,170.)

The four service models were tested by executing each model in collaboration with the third-sector operators. Each model included six to nine art interventions. Obtained results were examined, and changes were made as needed. Research results showed, that participants felt the art activities were meaningful and art activities activated their memory, allowing them to learn something new. Participants described having a new kind of approach to art and art had a positive effect on their vitality. Art also brought positive changes to participants mental alertness. Group setting, and support of others were experienced as meaningful. Activities were experienced important way to organize participants life experiences. *Art and Culture-Keys for Better Brain Health* research have provided new knowledge about combining art, culture and brain health. In conclusion art and culture can provide keys for promoting brain health. (Malmivaara & Kivelä 2015: 30-32, 46, 187, 191.)

Music therapeutic caregiving (MTC) is when caregivers sing for or together with persons with dementia during caring situations. Hammar et al. (2010) studied professional caregivers experiences for taking care of people with dementia during morning care situations with and without MTC. Six caregivers from two care homes in Sweden participated in the study. Group interviews with staff were conducted after the care situations. Morning care situations without singing had different kind problematic behaviors from persons with dementia and caregivers feeling of reward of the work was limited. When caregivers sang during morning care situations persons with dementia were more responsive and both the persons with dementia and caregiver had positive emotions. Caregiver felt appreciated. MTC can be a method to use promoting wellbeing and communion for everyone involved in caring situations in dementia care. (Hammar et al. 2010, 98;100;107-108.)

Gross's et al. (2015) study was looking for evidence if California's Orange County Alzheimer's Associations art activity program called *Memories in the Making* had carry-over effects beyond the art class. Study participants were people with middle to late stage dementia in long term care in Wichita Falls Texas. Seventy-six dementia residents attended 1-12 times at weekly art classes. Art classes were facilitated by university student interns with backgrounds in both psychology and art. Participants were provided at each session watercolor painting materials and were encouraged to paint freely or copy a picture provided for that day's session. For evaluation tool study used Greater Cincinnati Chapter Well-Being Observation Tool developed by Kinney and Rentz (2005). This tool was used to assess the effects of art activity on seven domains of well-being. Interns reported significant improvement from the beginning to middle and end of the program on five well-being domains. Staff reported though no significant changes in resident well-being across 12 -week program. Observations on the study indicate that the art program was beneficiary for some participants, even if it did not last long. Art program gave participants contentment and sense of involvement. All long-term care homes that participated in the art program incorporated *Memories in the Making* sessions in their weekly activities. (Gross et al. 2015:27,31, 40-42, Kinney & Rentz 2005.)

3 SUOMI-KOTI

Suomi-Koti is a non-profit Seniors Centre, that provides multi-level care and services, housing and activities for the Finnish community in Toronto. Suomi-Koti has 88 apartments as life-lease or on rental basis in 2nd to 6th floor. Long-term care Facility is on the 7th floor, where nursing home has 34 resident places and three respite places. (Suomi-Koti 2018.)

Admission to Suomi-Koti is through the Ontario's Local Health Intergration Networks (LHIN). LHIN are the health authorities responsible for regional administration of public healthcare services in Ontario, Canada. LHIN plan, integrate and fund local health care and improve access and patient experience. (Ontario Local Health Intergration Networks 2018.) Suomi-Koti is a ethno-specific nursing home with preference on Finnish and Estonian residents. Suomi-Koti provides care with programs in a Finnish cultural and linguistic environment. Most of the daily activities provided are in Finnish and Suomi-Koti celebrates all Finnish holidays. Finnish pastor's or volunteer come once a week to have a worship service with the residents. Most of the volunteers can speak Finnish and residents have someone to talk to in Finnish most days. Many months of the year there are nursing and social service students from Finland doing their work practise. very staff member, especially care staff can speak some basic Finnish words to help residents to be understood in their daily life. (Suomi-koti 2018.)

The Suomi-Koti nursing home has a person-centred care approach and it is beneficial for all the residents. The Suomi-Koti nursing home care staff are trained in The Gentle Persuasive Approach (GPA). It teaches staff how to invite residents to do things and participate. Suomi-Koti is an ideal place for Finnish-Canadians who have dementia, because there is always somebody who knows some Finnish and the residents are understood. Even though most Finns who are living in Suomi-Koti have been living in Canada a long time they still often like to speak Finnish and be around other Finns. They seem to be very rooted in Canada with their families and yet have not forgotten their birth country. It is important to keep having daily activities in Finnish, while more and more residents developed advanced dementia. It gives residents comfort and security to be able to continue speaking Finnish for their whole life span.

4 PURPOSE OF THE STUDY

The purpose of this study is to find out what kind of activities residents like and what kind of activities they want to participate in at Suomi-Koti. The three groups interviewed are: residents, volunteers and nursing staff. Getting answers from each group will give Suomi-Koti valuable information about their activities and the produced information will help Suomi-Koti to provide a good program of resident focused activities. The study results will also help improving volunteer coordination and the work that the volunteers are doing.

4.1 Study purpose

This study is asking questions to understand what the key elements of person centered activities for people with dementia in long term care are and how do the different groups (people with dementia, volunteers and care staff) realize and experience person centered care and is it making a difference in residents' lives. Study is also gathering information specific to Suomi-Koti and its program. Thus, there are three main groups of people that have been interviewed: residents in long term care, the volunteers who lead the activities, and the care staff who take care of the residents at Suomi-Koti. Each group has a different role and a different perspective. For this reason, each group were asked questions to try to get a clear picture for Suomi-Koti specifically as well as insights into effective person-centered activities for people with dementia in long term care.

4.2 Key questions of the study

Study is looking in to what kind of activities are stimulating and activate with people with dementia in long term care. To this end the residents has been asked questions to understand which activities they enjoy and are their needs being met. It is crucial that the voices of the residents are heard. Stud also asked volunteers their perspective on the activities offered as well as input on the training and support offered through Suomi-Koti for their activities. Questions for the nursing staff are to understand how nurses see activities effecting and improving resident's life.

Key issues for the residents: *Do the activities provided at Suomi-Koti meet residents needs and wishes? Which activities offered at Suomi-Koti residents enjoy the most?*

Key issues for the volunteers: *Are volunteers seeing, that Suomi-Koti is providing person-centred activities? Do the volunteers want to change or improve any activities that are provided at Suomi-Koti? Do volunteer's feel supported in their work with the residents?*

Key issues for members of the staff: *Are care staff seeing, that Suomi-Koti is providing person-centred care? Are care staff seeing activities offered at Suomi-Koti helping residents and how?*

This study wants to find out if the residents are benefitting from activities that are offered at Suomi-Koti. This is often seen by the care staff and to a lesser extent volunteers who might see an improvement in the daily live of the residents.

5 METHODS

This was a qualitative, theme study with semi-structured interviews with Suomi-Koti nursing home's residents, volunteers and care staff. Digital recorder was used when doing the interviews and the full interview was recorded.

The purpose of qualitative study is to explain or understand beliefs and behaviour, identify processes and understand the context of people's experiences. Because of in-depth nature of qualitative study, not many participants are needed, as the purpose is to get depth of information by asking participants experiences on the study topic. (Hennink et al. 2011, 17.)

The in-depth interviews involve direct interaction with individuals on a one-on-one basis and only the interviewee shares their story and the interviewer's role is to elicit the story. In depth interviews are good when looking for information on personal experiences from people about specific issue and trying to capture individual voices and stories. (Hennink et al. 2011,109-110.) Semi-structured interviews are useful for collecting information on people's opinions and experiences. A semi-structured interview provides reliable and comparable qualitative data because it allows informants the freedom to express their views in their own terms and feelings. Benefits of the qualitative approach are that the information collected can be rich and has a deep insight into the issues and questions at hand.

5.1 Data collection

Study permit was received from Suomi-Koti in September 2017 (appendix 5). Each participant was asked to a written consent before doing the interviews (appendix 4). Total of interviews were 30: 12 residents (11 Finnish and 1 Estonian), 10 volunteers (all could speak Finnish) and 8 care staff members, whose English was not their mother language.

Residents were interviewed in their own rooms. Care staff were interviewed in their breakroom or in one of the offices, sometimes it was noisy and other people stopped in and we had to stop for a while. Seven volunteers were interviewed at Suomi-Koti nursing home and three at their homes. Doing the semi-structured interviews personally, author was able to simplify any questions that might not been understood by interviewees, thus

ensuring mutual understanding. Because of that, more accurate data was collected. (Dörnyei 2007, 143).

5.2 Analyses

Qualitative data analysis is described as “creative”, “flexible” and involving “chaos”. It refers to the interpretive nature of analysis. This includes making sense of people’s many and contrasting perspectives. It develops a “story” from the data, but not in the fictional or imaginary sense. There is a cogent presentation of people’s experiences that reflects the complexity and irrational nature of human behavior. Both the creative and the scientific aspects are important in qualitative data analysis and there has to be a balance between them to conduct good quality analysis. (Hennink et al. 2011, 205-206.)

After conducting the interviews, they were downloaded into a computer. Online tool called *Transcribe* was used to dictate each interview into word file. Each speaker was labeled, so they could differentiate by a letter, example R1, R2, R3, (resident), V1, V2 (volunteer) and S1, S2 (staff). After that all the 30 interviews were printed and rising themes were looked at. The first reading of data can identify more explicit codes and more subtle codes, or underlying concepts are typically identified after several close readings of the data (Hennink et al. 2011, 221). To analyse the study results content analyst was used.

A code can be a topic, idea, concept or process that is evident in the data and codes are topics discussed by interviewee’s and are develop by reading the data. Some codes are raised by interviewee (called inductive codes) and others have been created by interviewer using topics, that were derived from literature and theory (called deductive codes). Identifying codes allows researches to identify the range of issues raised in the data, and understand the meanings attached to these issues by interviewees. Codes are used as markers to index entire data set so that you can locate every place in the data where specific issues are discussed. It also helps to conduct a focused analysis of a specific issues in the data. (Hennink et al. 2011, 216-229.)

After coding data was categorised. Categorization involves identifying codes with similar characteristics and then grouping these together into categories. Categories represent a higher-order grouping of data and begin building frameworks to explain and develop theory about the research issues (Hennink et al. 2011, 245-246). Each participant group’s interviews were grouped and analysed separately, and Excel sheet summaries were

written (Appendix 6). The themes from the resident group were used as comparison for the information from the care staff and volunteers.

5.3 Validity, reliability and ethical considerations

Residents, volunteers and nursing staff were asked for their consent and explain the purpose of the interview and how the information will be used. It was explained no names will be used and collected data will be strictly confidential and anonymous and participating in the research is entirely voluntary. Writer knows every resident, volunteer and nursing staff from having done her last two work practices at Suomi-Koti nursing home.

Suomi-Koti has 34 residents and three respite beds and 12 residents were interviewed. This will give a good reliability for the research. Volunteer interviews were harder to do on a large scale because a lot of the people volunteer only casually. Some of the volunteers were on vacation at the time of the study. If interview period would have been longer, there could have been more volunteers to be interviewed. Volunteers in this study volunteer weekly and their views were valuable. Ten volunteers and eight care staff members agreed to be interviewed. Maybe more staff members would have been possible to get interviewed but it was often difficult for staff to fit time for it. Since every interview was recorder original "voice" of the interviews was not lost and there is smaller chance of misunderstanding what the interviewee was saying. Study was validated by getting enough residents, volunteers and care staff's opinions to similar issues emerge in each group.

Same questions were asked from each resident. Not all residents answered to all the questions, but most did. One resident answered in English and 11 in Finnish. There were separate set of questions for the volunteers and the care staff, who all answered in English. Some of the questions for volunteers and staff were the same but not all. Author was avoiding asking leading questions and because of that got sometimes very short answers. A pilot interview for residents' questions was conducted outside the nursing home with a Finnish speaking person with dementia and it gave the interviewer a chance to clarify the points they were making. All the questions were reviewed and approved by Suomi-Koti nursing home in advance. Author's teacher also reviewed the questions before interviews were conducted. Interviewees were given as much as time they needed. Staff members were often in a hurry but were surprised how easy the interview felt for them and in the end, they would have been willing to answer to more questions.

Average time for each interview was 15 minutes, interviews lasting 10-25 minutes. A good qualitative interview has two key features: it flows naturally, and it is rich in details (Dörnyei 2007, 140).

In the literature there were not found exactly same questions asked, so these interviews should provide new results and be useful for Suomi-Koti. Results were compared with other studies done and used academically valuated research to help understand and clarify study questions and findings.

6 RESULTS

The key elements for person-centred activities for people with dementia are:

- Residents enjoy the activities provided; the activities are based on the residents' wishes; and the activities are both creative and stimulating
- Resident feel they are included in a group and their lives matter
- Volunteers and care staff leading the activities know the residents well enough to engage and adjust the activities based on residents wishes and are there for the residents

The time care staff, that was interviewed, have been working at Suomi-Koti varied from 2-25 years and average year working at Suomi-Koti was 13 years. Only one from eight care staff members had any special training that would help them do activities with residents and five would be interested having training. When asked why they would not be interested on training, care staff member said they have enough work already. One care staff member said she has been working so long that it is enough, what she has.

Volunteers had a wide range of years volunteering at Suomi-Koti from 30 years to two. Average time volunteering was 13,5 years. All volunteers that were interviewed for this study could speak Finnish.

6.1 Residents

These group of questions in this study are specially trying to identify stimulating and activating ways to do activities with people with dementia. Study asked twelve residents (11 women and 1 man) nine different questions.

The residents were asked what makes them happy and nine out of twelve said family and friends makes them happy. Health was important to six resident as well. Male resident said what makes him happy is to do what he likes.

When asked if residents like spending time with other residents eight residents said they like spending time with other residents and two liked it sometimes. Two of the residents did not like to spend time with other residents and when asked why they said:

" I like to be alone", I don't know other residents"

Residents were asked to tell what kind of activities they enjoy and three activities popped up the most (Figure 2) : Ten residents preferred one-on-one activities with volunteer and if offered would do it , seven residents mentioned music and six resident enjoyed religious events. Other events residents enjoyed were reading (4), exercise (3), handcraft (3), games (3) and small group activities (2).

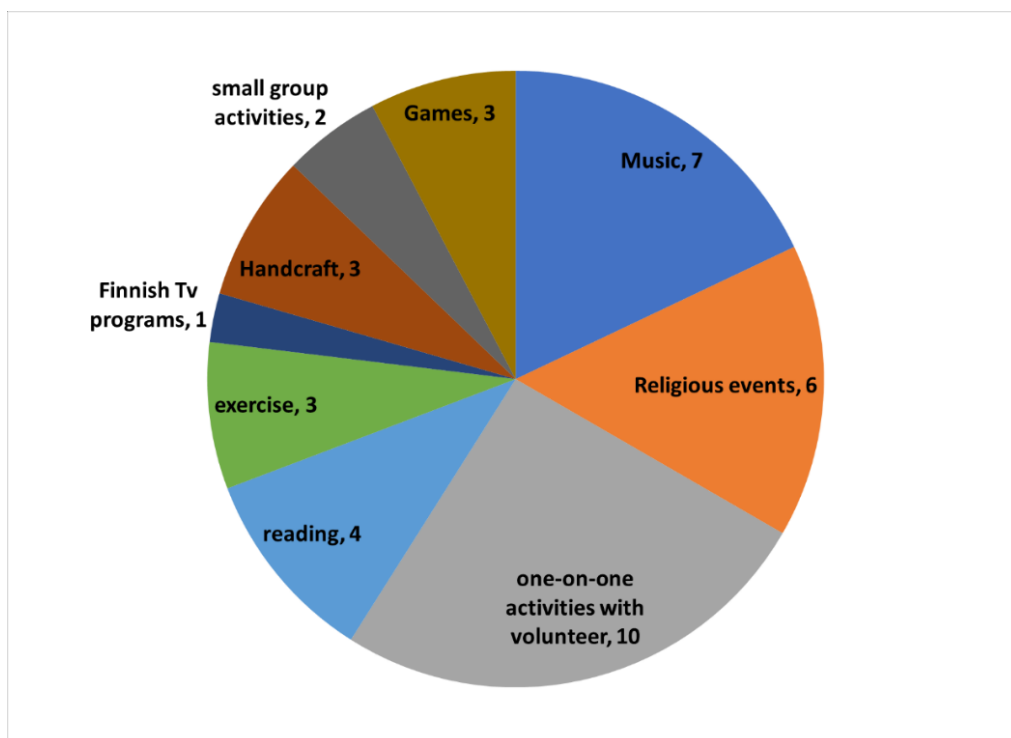


Figure 2. Activities enjoyed by the residents at Suomi-Koti nursing home. *“What kind of activities do you enjoy in at Suomi-Koti?”* Total of residents answered:12. Total of activities mention by residents: 9.

When asked residents about their hobbies when they were younger seven said they did different kind of physical activities. Six resident did something with their hands , like sewing , handcrafts and drawing. Music, singing and going to church were mentioned as well. One resident could not remember having hobbies as a child and one said she did not have time for hobbies. On hobbies that residents use to have when they were younger seven residents said they have not been able to continue at Suomi-Koti, two could not say and three said they were able to continue their hobbies at Suomi-Koti.

Residents gave different reasons why they could not continue their hobbies at Suomi-Koti. Two said they were not in good shape and one resident said there are no equipment or it is not possible at Suomi-Koti. Two residents did not have any specific reasons for not continuing their hobbies at Suomi-Koti.

Residents were asked if there is an activity currently at Suomi-Koti that they would like to have more in the weekly schedule. Residents said they would like more of music (4), reading (2), small coffee club (1), bingo (1), singing (1) and Sunday devotion on TV (1).

When asked if there is an activity they would like to add, that is not currently offered, some residents mentions already provided activities, like music, religious programs, movies and singing. One resident said she would like to be able to play cards. Another residents said she likes baking and it would a nice to do that. Half of the residents did not want to add any new activities.

Six out of twelve residents liked all the activities provided at Suomi-Koti. Resident were asked if there is an activity they don't like. One resident said he does not go to activities he does not like,so it doe snot matter what is offered. Another resident said she does not like trivia and third resident did not like when activities started late. Resident said about activities;

"Hard to say, sometimes it is too much"

and other: *" I do not like dancing and live music by that young man"*.

Study asked residents if they would like to spend more one-on-one time with a volunteer and if so, what would it be. Ten residents would like to do one-on-one activity with volunteer, if it is offered. Three resident would like to spend that time reading together, one said having a friend and talking with would be nice, three would like to do something with their hands, one resident liked to exercise and one would like to visit her old apartment together with a volunteer.

Residents were asked if they were asked about their wishes about activities planned, and seven said no, four resident said yes they were asked. One resident said sometimes she was asked.

" No, nobody listen me anyway".

"Yes, I've been asked enough".

6.2 Volunteers

Volunteers are doing most of the activities at Suomi-Koti. Currently activities that volunteers are doing are spa, bingo, reading club, fitness, trivia, singing, religious programs, one-on-one activities, music and birthday parties and some outings. There

are occasional special activities with baking or craft but they are not offered on regular basis.

Ten volunteers were asked twenty different questions for this study. Nine volunteers that participated in this study volunteer once a week and one volunteer does it three times a week. Each volunteer has been also volunteering at special events.

Volunteers were asked if they have any special training that would support their volunteer activities at Suomi-Koti and what that is. Three volunteers use to be a registered nurse (RN) and two were personal service workers (PSW). Five volunteers said they had no special training, that would support their volunteer work.

Study also asked if volunteers customize the activities to fit residents' personal needs, and if they do how. Six volunteers said they do customize activities as needed. Volunteers that do customize activities five out of six try to do whatever residents ask them to and one volunteer changes the activity to fit resident's physical ability to do the activity. Four volunteers do not customize the activities they do with the residents. A volunteer who hasn't customize activities said activities are pre-planned and have been running a long time as is. Other volunteer said activities run smoothly and there is no need for a change.

"If residents need something I try to give it to them"

"I can't say I'd customize because it's already traditional organization that makes our activity moments and it can only be done one way"

When asked about preparing for the activity ahead of time only one volunteer said she has prepared for the activity and nine said they did not. But if preparation is needed every volunteer said they would have the time to do so.

Every volunteer said they get help and support from the staff. Support varies from getting residents out of bed (3), setting up (2), taking residents to washroom (2), attending activity (1), help on palliative care (1) to answering volunteers' questions (1).

Volunteers were asked if they would like to do more as a volunteer and only two said yes. Most feel they are already doing enough and they have no time doing more. All volunteers said activities are important to have for residents in long term care.

Study asked if volunteers would like to add any new activities for the residents at Suomi-Koti. Five would like to add a new activity and five would not. Activities volunteers said: music (2), one-on-one (2), knitting and painting (1).

Eight volunteers said they receive feedback from the residents, which was thank you's (5) and smiles (3) and generally feedback was positive. Two volunteers said they did not really receive feedback from the residents.

Volunteers were asked if they saw any change in the mood or behavior of residents after an activity. Seven volunteers said they did see a change and three said no they did not see any change. Those who did not see any changes said it was because they were not there long enough to see it. The changes volunteers do see are that residents are happier (4), talkative (3), more alert (2) and feeling better (1).

“Residents are more active, and they are more talkative, and they are more opinionated what they want”.

Volunteers said activities that they think are good for people with dementia are music, one-on-one activities, activities to do with your hands, exercise, baking and talking. All volunteers but one said residents actively do participate in the activities provided. One volunteer did not know how actively residents participated in activities.

Several obstacles for providing activities were mentioned. Two volunteers mention lack of space. Two volunteers said lack of volunteers create a problem doing activities, lack of staff was also said by one volunteer. One volunteer said that group can be too big for one person to handle and two said residents' level of dementia also can be a barrier for providing activities. Two volunteers did not see any obstacles for providing activities at Suomi-Koti.

When asked from the volunteers if they would be interested doing one-on-one activities with the residents in the future four said yes and two out of those were currently doing that activity already. Six volunteers said they would not like to do one-on-one activities.

Volunteers who were interviewed for this study 50 percent were willing to help with feeding in the future and 30 percent said maybe. Only two volunteer said they do not want to help feeding residents at meal times.

Study asked volunteers how do they see the interaction between residents and the care staff at meal times. Seven volunteers said they though interaction was good, two said

they are not present at meal time and do not know. One volunteer said care staff does not have enough time with residents at meal time.

" I think it's very good. A lot of people even though they are not Finnish, they know enough words to encourage people to eat".

Volunteers were asked if they would like to talk about anything else about the activities provided at Suomi-Koti and four said no. One said there is a need for more volunteers, but lack of parking can be a problem because volunteers do have hard time finding parking close to Suomi-Koti. Another volunteer suggested to have more singing, one volunteer was hoping residents could go to sauna downstairs at Suomi-Koti. Two volunteers said Suomi-Koti has a lot of activities, especially when comparing to other nursing homes.

6.3 Care staff

Eight care staff members were asked twelve different questions about activities provided and about person-centred care at Suomi-Koti.

Every member of the care staff thinks activities help residents at Suomi-Koti and activities have a positive effect. Residents are more alert and active after activities.

"They help residents look forward what's going on and something to look forward to"

"Residents feel like they are doing something, and they are talking"

Seven out of eight care staff members sees there are change in the mood or behavior of residents after an activity. Residents are happier, talkative, more positive. One care staff member said residents are more tired after an activity. Care staff sees positive changes after an activity.

"They are participating and feel they are getting involved in something"

"They feel like they are at home"

Care staff listed several activities that are good for people with dementia: reminiscing (3), talking (2), exercise (3), one-on-one (2), music (2) and activities from resident's past (2).

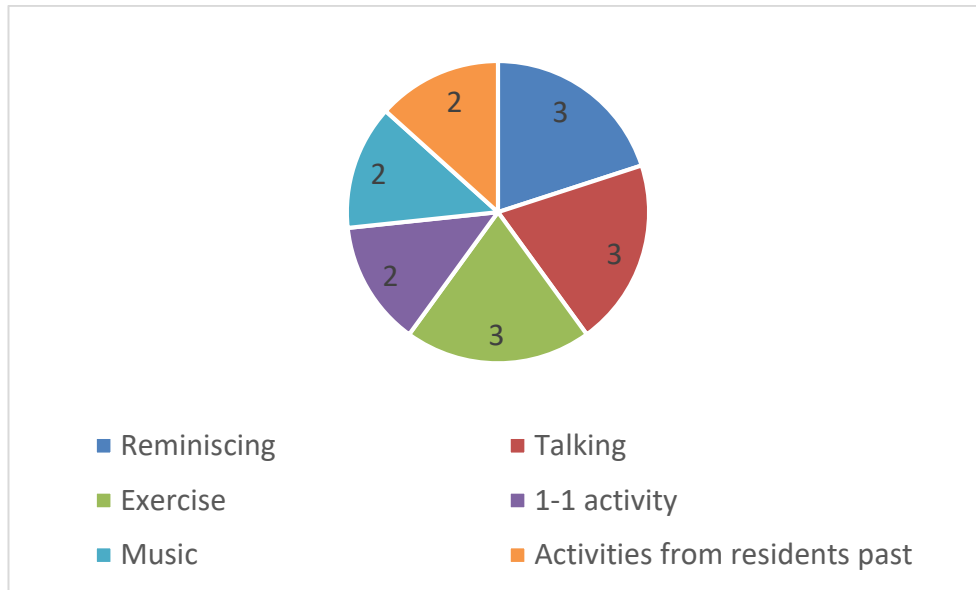


Figure 3. Activities care staff think are good for people with dementia in long term care. Total of care staff answered:8. Total of activities mention by care staff: 6.

Study asked the care staff what the effective ways are to maintain activities, that they think help residents. The consistence and routine of the activities was the most said, six out of eight thought those were the ways to maintain activities. Other ideas were keeping resident mobile (1), less noise (1) and making sure residents are assisted to the activities (1).

“Having a routine for the residents, so they know what is going on that day”

Care staff were asked if they wanted to add any new activities. Five out of eight care staff members said yes. Activities that were suggested were: painting, more music, one-on-one activities, games, more physical activities, Sunday spiritual programs, reading stories, something more stimulating and knitting.

Everyone from care staff would like to participate in activities with the residents, which could be a good resource. Four care staff members were willing to participate any activity, two for physical activity, one reminiscing and one said bingo and reading would be nice to attend.

Care staff was asked if they have any special training that would help them to do activities with the residents. Only one care staff member said to have training to do activities with the residents. If offered seven would like to have more training.

Study asked if there are any barriers or obstacles when providing activities at Suomi-Koti. Four care staff members said not enough space was an obstacle when providing activities. Two care staff members said there are not enough volunteers and one mentions that activities are not spread equally during the day. One care staff member said scheduling activities too close to each other can be an obstacle because residents are too tired to participate.

When providing activities, it is important that care staff knows what is going on and when. Care staff was asked if information about activities are easily available at Suomi-Koti and seven out of eight said yes. Only one said no and she does not know what activities are going on daily. When asked how she would like to be informed about them, she said that having a monthly bulletin clearly at the nursing station and updates about changes would help.

Information about residents past life and likes are in a resident's care plan. Care plan includes all aspects of resident's care, diagnoses, nutritional, dietary, social, medical, spiritual, restorative and personal care. In Suomi-Koti two care staff members thought that their care plans have enough information about residents. Three care staff members said maybe care plans have enough information about residents and two care staff members said they don't know. One care staff member said there is not enough information.

"I think our care plans have a lot of information, from the past to the present".

"Not really. I don't think enough time is invested in the care plan. To really get in-depth thing what are their likes and not, you know".

Last question for the care staff members was to ask what person-centred care means to them and do they see it at Suomi-Koti. Seven care staff members said Suomi-Koti is doing person-centred care, and two had to be explained more about it to understand its meaning by author. It was hard for some care staff to explain what person-centred care means to them and four could not really explain it. One care staff member said it means, that residents needs are been mostly met and staff tries to do as residents want. Another care staff member said person-centered care means you are on resident's schedule and resident can get up when they want. Third staff member said you are focusing the whole aspect of person and residents are their priority. Fourth care staff member said, that person-centred care gives her affective way of taking care of an individual resident.

“Doing person-centred care, we make them happy and content and I think behaviour will be minimized”.

“I think it’s good. This is our second family, no fighting. It is very peaceful and quiet, that person-centred care works here “.

6.4 Conclusion

Several activities that residents talked about enjoying the most are currently offered at Suomi-Koti. And when asked about new activities to add, each group mostly mentioned same activities, that are already offered. People interviewed for this study would like more of what is already offered and not so many new activities.

Both volunteers and care staff members said activities that are good for people with dementia are music, talking, reminiscing and exercise. Most liked by residents was also music and one-on-one activity.

From each group interviewed the one-on-one activity was mentioned several times. There is a need for the resident to have someone to spend one-on-one time with them, but there are not many volunteers willing to do so and here residents are not getting what they wish for. Only two volunteers interviewed for this study are currently doing one-on-one activities and four in all would be willing to do the one-on-one activity.

All volunteers and care staff members thought activities do help residents and most said activities bring positive results regarding residents’ mood and behavior.

Volunteers and care staff saw same kind of barriers and obstacles while providing activities: not enough space and not enough volunteers or staff.

7 DISCUSSION

This study looked for key elements of person-centred activities for people with dementia in long term care in a Finnish nursing home in Toronto. Study wanted to look if Suomi-Koti was providing activities based on residents needs. It was also important to hear volunteers and care staff's opinions about activities at Suomi-Koti. Goal was also to give Suomi-Koti information, that they could use to make sure activities provided are person-centred and if something needs to be improved or changed.

Key elements that make person-centred activities found in this study was that residents should enjoy the activities provided, the activities are based on the residents' wishes, and the activities are both creative and stimulating. Resident should feel they are included in a group and their lives still matter while living in a nursing home. Volunteers and care staff leading the activities should know the residents well enough to engage and adjust the activities based on residents wishes and to be there for the residents.

Key questions in this study was, that do the activities provided at Suomi-Koti meet residents needs and wishes and which activities offered residents enjoy the most. These questions were answered clearly. Six out of twelve did not want to add new activities and mostly new activities wished were already offered and residents just wanted more of them. Most popular activity residents said they enjoyed was one-on-one activity with volunteer. Only forty percent of volunteers interviewed said they would like to do one-on-one activities with the residents. To meet residents wishes and have more person-centred activities Suomi-Koti should try to recruit more volunteers, current and new, to do one-on-one activities with the residents. Suomi-Koti has about 30 active volunteers, whom of ten were interviewed for this study.

Music was a popular activity among participants and when asked what activities should be added from the residents, care staff and volunteers, music was mentioned several times. Even though Suomi-Koti is offering music, there is not enough of it based on this study. It would be good to encourage care staff to include music on some form during daily activities with residents and have more weekly activities with music.

This study was geared to learn if the volunteers wanted to change or improve any activities that are provided at Suomi-Koti and do they feel supported in their work with the residents. Every volunteer felt they are supported by Suomi-Koti staff and they

receive help if they need it. Volunteers did not want to change much of the activities, mostly increase current ones.

Volunteers should be encouraged to read the results of this study. Suomi-Koti will also get an executive summary of this study, which could be given to the volunteers as well to read. Volunteers could be offered to have more information about residents and remind volunteers that it is okay to change the activities as residents want, even though some activities have been running the same way a long time.

Study wanted to know if care staff members are seeing, that Suomi-Koti is providing person-centred care and are care staff seeing activities offered at Suomi-Koti helping residents and how. Study made care staff members to think about the meaning of person-centred care, which was not clear to them all. Study showed care staff think activities are helping residents in a positive way.

Care staff indicated that they would like to participate activities with the residents. Singing to or with residents at any time could be a nice experience for both parties involved and it would increase person-centred care. This is something that could be care staff encourage to do. Care staff mentions there is no consistence on Sunday service provided on TV due to lack of volunteers to put it on. In the future morning care staff member could be signed to make sure Sunday church service take place on TV and not rely on volunteers to do it.

Question for the care staff about what person-centred care means to them could have been asked differently. The way it was asked made care staff ask clarifications and it was hard for them to answer directly to the question. Better wording might have been more helpful to clarify the question. However, this did not influence the final conclusions in this study.

Suomi-Koti should investigate all its currently offered activities and make some changes to give even more person-centred care and use the findings on this study. There are many good activities already at Suomi-Koti and with some changes in how activities are given improvement would happen.

This was a small qualitative study and the findings of the study are applicable to Suomi-Koti nursing home. But the implications for practice could be relevant to many other similar nursing homes.

For further study it would be interesting to do a survey in a year if Suomi-Koti has increased its person-centred activities and if there are more volunteers doing one-on-one activities with residents.

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INTERVIEW QUESTIONS / RESIDENTS

1. Mikä tekee sinut onnelliseksi?
What makes you happy?
2. Tykkäätkö viettää aikaa muiden asukkaiden kanssa? Jos et, mikä on pääsyy siihen?
Do you like spending time with other residents? If not, what is the main reason?
3. Millaisista ohjelmista sinä pidät Suomi-kodissa?
What kind of activities do you enjoy in at Suomi -Koti?
4. Millaisia harrastuksia sinulla oli kun olit nuorempi? Oletko pystynyt jatkamaan niitä täällä Suomikodissa? Jos et, minkä takia et ?
When you were younger, what kind of hobbies did you have? Have you been able to continue your hobbies here at Suomi-Koti? If not, what is the reason for that?
5. Onko jotain ohjelmaa tai toimintaa, mitä haluaisit lisätä, jota ei vielä tarjota Suomi- Kodissa?
Is there an activity you would like to add that is not provided yet at Suomi Koti?
6. Onko jotain nykyisistä toiminnoista/ohjelmista , mitä haluaisit enemmän sisällytettävän viikottaiseen ohjelmatarjontaan täällä Suomi-kodissa?
Is there some activity we currently have that you would like to have more in the weekly schedule at Suomi-Koti?
7. Onko jokin toiminta / ohjelma, mistä et pidä Suomi-kodissa?
Is there an activity you do not like at Suomi-Koti?
8. Haluaisitko saada enemmän tekemistä kahdestaan vapaaehtoisen kanssa? Jos kyllä, mitä se voisi olla?
Would you like to spend more one-on –one time with a volunteer? If yes, doing what?

9. Onko sinun toiveitasi kysytty ohjelmia suunniteltaessa ?

In regard to the activities which have been planned,
were you asked about your wishes?

INTERVIEW QUESTIONS FOR THE VOLUNTEERS

1. How long have you been volunteering at Suomi-Koti?
2. How often do you volunteer at Suomi-Koti?
3. Have you had any special training that would support your volunteer activities at Suomi-Koti? If not, would you like to?
4. What kind of activities do you do/organize at Suomi-Koti?
5. Do you customize activities regularly to fit the resident's personal wishes at Suomi-Koti? If yes, how? If not, what is the main reason for not doing so?
6. How do you prepare the activities for the residents at Suomi-Koti?
7. Do you have enough time to prepare for the activities?
8. Is there something you would like to do more as a volunteer?
9. Would you like to add any new activities for the residents? If yes, what?
10. Do you get feedback from the residents? If yes, what kind?
11. Do you see any change in the mood or behaviour of residents after an activity? If yes, what kind of change?
12. Do you get help and support from the staff if you need it? If yes, what kind of help?

13. What kind of activities do you think are good for people with dementia in long term care?
14. How do you view the importance of activities in long term care?
15. In your opinion, how actively do the Suomi-Koti residents participate in the available opportunities?
16. What barriers/ obstacles do you see when providing activities at Suomi-Koti?
17. Would you be interested in doing one -on -one activities with residents in the future?
18. Would you be able to help with feeding the residents at meal times?
19. When /if you are present at meal times, how do you see the interaction between residents and the staff?
20. Is there anything you would like to talk about the activities provided for the residents?

INTERVIEW QUESTIONS FOR THE NURSING STAFF

1. How long have you been working at the Suomi-Koti nursing home?
2. Do you feel the activities at Suomi-Koti help residents? If yes, how?
3. Would you like to add any new activities at Suomi-Koti? If yes, what?
4. Do you see any change in the mood or behaviour of residents after an activity? If yes describe what kind.
5. What kind of activities do you think are good for people with dementia in long term care?
6. Would you like to participate in any of the activities with the residents? If not, what is the main reason for not participating? If you do, what kind of activities do you participate in?
7. What barriers/ obstacles do you see when providing activities at Suomi-Koti?
8. What are effective ways to maintain activities that you think do help residents?
9. Do you think the care plan has enough information about the resident's interests in different activities?

10. Is the information about daily activities easily available at the Suomi-Koti nursing home? If not, how would you like to be informed about them?
11. Have you had any special training that would help you do activities with the residents at Suomi-Koti?
12. What does person centered care mean to you and how do you see it here at Suomi-Koti?

Interview Consent

This interview is part of Pia DeMartini's research to understand what are the key elements of person centered activities for people with dementia in long term care and how do the different groups (people with dementia, volunteers and nurses) realize/experience person centered care and is it making a difference in their lives. She wants to find out what kind of activities residents like and what kind of activities they want to participate in at Suomi-Koti. The answers from the interview be used in Pia DeMartini's bachelor's thesis study "Key Elements for Person Centered activities for people with dementia in Long Term Care". They will also be reported to Suomi-Koti to provide valuable information about the activities at Suomi-Koti and the produced information will help Suomi-Koti to provide a good program of resident focused activities. The research results will also help improving volunteer coordination and the work that the volunteers are doing.

By signing this form I agree to be interviewed by Pia DeMartini.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.

I understand that my responses will be kept strictly confidential. I understand that my name will not be linked with the research material, and will not be identified or identifiable in the report that results from the research.

I agree for this interview to be recorded. I understand that the audio recording made of this interview will be used only for analysis and that extracts from the interview, from which I would not be personally identified, may be used in any presentation or report developed as a result of the research.

I understand that no other use will be made of the recording without my written permission, and that no other than researcher will be allowed access to the original recording.

I agree that my anonymised data will be kept for future research purposes such as publications related to this study after the completion of the study.

Date

Participants signature

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RESEARCH PERMIT REQUEST

6.9.2017

Research permit request

I am studying social work at Turku University of Applied Sciences in Finland. I will graduate with a bachelor of social services by Fall 2018. I am requesting permission to do the research for my thesis at Suomi-Koti nursing home in Toronto this fall during my work-study. In my thesis I am investigating the key elements to make activities that enhance the lives of elderly people with dementia. This research will help highlight if activities improve the lives of the elderly and how. Suomi-Koti has many activities and long history of volunteers planning and supervising activities. They can provide information and a perspective on what works and what does not. In many long-term care facilities, activities for people with dementia are not stimulating and are not something the elderly themselves want to do.

This thesis research will be a qualitative study and I will do theme based semi-structured interviews with residents, volunteers and nursing staff. The interviews will be conducted with people who agree to participate. Interviews will be recorded but all information will be handled anonymously. I am coordinating this research with Arja Tolppanen from Suomi-Koti and my teacher Anne Merta from Turku University of Applied Sciences.

I will give permission for this research



I will not give permission for this research



Toronto, Sept. 6/17

Time and place

Paul Shone

Paul Shone, Director of care Suomi-Koti

*Leila Parviainen RN MAJ BA
 Administrator*

	What makes you happy?	Do you like spending time with other residents?	Why don't you like spending time with other residents?
R1	My legs would get better and I could dance	yes	
R2	When you are healthy, day that is good without fuss. When my family is happy	Yes	
R3	To stay healthy and helping people, good friends	yes	
R4	Faith, my children	yes	
R5	Stay bit healthy, children would be okay	yes	
R6	When my kids visit and hug me, my kids	No	I like to be alone
R7	Live and have healthy live, family	some	we don't match together
R8	When my daughter comes visit me	some	
R9	When I can visit my old home. Here is good too	no	I don't know other residents
R10	I can do what I like	yes	
R11	When I have lots of good friends	yes	
R12	My family and when all goes well	yes	

	What kind of activities do you enjoy at Suomi-Koti?	What kind of hobbies did you have younger?	Have you been able to continue your hobbies at Suomi-Koti?
R1	nature movies and music	dancing, handcrafts	No
R2	any kind	cross country skiing, sewing	No
R3	exercise, singing choir, devotions, spiritual activities	knitting, crocheting, sewing, dancing, singing.	No
R4	serious ones with word of God	I liked acting but War came and all stopped. Music.	No
R5	that makes you feel good.	I liked to sing and go to church. I liked to travel and have dinner guests.	No
R6	music, anything Finnish program.	not much time for hobbies	
R7	watching TV, listening music.	I can't remember	
R8	devotions by pastor, singing.	reading, gardening, sports.	yes, some
R9	devotions	cross country skiing, swimming, travelling	no
R10	I can't think of anything righ now	I liked drawing and painting	yes, some
R11	trivia	sports, running.	no
R12	reading poems, dancing, spiritual program	cross country skiing, writing poems, hand crafts	yes,some

	What is the reason you have not been able to continue your hobbies at Suomi-Koti?	Is there an activity you would like to add that is not provided yet at Suomi-Koti?	Is there some activity we currently have that you would like to have more?
R1	my legs	Old and new Finnish movies	Music
R2	No equipments	I have no energy for anything	All is good, I have no energy
R3	not in good shape	I leave it to others to decide	small coffee club,reminsicing
R4	Not possible here	more music and serous program	music.
R5		singing	bingo, game called skipper
R6		card games	I can't think of anything
R7		I don't think so	music.
R8	no special reason	I like to bake.	reading club
R9	no special reason	Not really, I like exercise	I like reading
R10		I don't know	I wish I could remember
R11		Here is lot	Kids would visit and sing
R12		I do not want anything	Sunday devotion on TV

	Is there an activity you do not like at Suomi-Koti?	Would you like to spend more 1-1 time with a volunteer?	What would you like to do on 1-1 with volunteer?	In regards to the activities which have been planned, were you asked about your wishes?
R1	all is good	yes	exercise	No
R2	All is OK	yes	I would like to read books	No
R3	no	yes	reading	yes
R4	I like it all	No		some
R5	When you have activities that starts late	yes	anything I can think and use my hands	no
R6	can't really say, TV room is too crouded	yes	reading finnish books	no
R7	If I don't like I don't go	I don't know		no, nobody listen
R8	dancing and live music by young man	yes	hand craft	no
R9	all is okey	yes	visiting my old apartment	yes
R10	I like it all	yes	painting	no
R11	hard to say, sometimes it is too much	yes	having a friend and talking	yes
R12	trivia	no		yes