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Musician and Dementia— an overview literature study on music and dementia from a musician's perspective

Introduction

At the time of writing this literature study, I am currently a second year student on the NAIP- European Master of Music Program. I am designing a creative participatory music project for elderly people with dementia as my final Professional Integration Project (PIP) in Stockholm, Sweden. I am a violist, a music educator, and as part of my educational background I have studied courses of psychology at Helsinki University. From these settings, this study aims to find answers to what kind of skills, qualities and understandings are needed for a musician working with elderly people with dementia, and what kinds of challenges they might encounter. According to my pre-understanding, dementia-related multi-disciplinary work requires a musician to have highly developed instrumental skills, improvisation skills and musical flexibility as well as empathy and strong interpersonal skills. The data of this study on a musician's role in dementia-related music-workshops is to be later applied for the development of the Music & Dementia-module of the NAIP- European Master of Music Program in the Netherlands.

The literature that this study focuses on consists of the following books:

- Garrett, P. (2009). *Can Music for Life enhance the well-being of people with dementia and develop the person-centered care skills of care workers?* MSc Dissertation: University of Bradford
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Berkshire: Open University Press.
- Zeisel, J. (2009). *I'm still here: Creating a better life for a loved one living with Alzheimer's*. London: Piatkus.

As a point-of-departure we will examine the standards of *The National Service Framework for Older People* by Britain's Department of Health, 2001 (Garrett, 2009:12). According to the document, elderly life is to be respected by supporting the persons' uniqueness and individuality in such social environment that provides services for their needs. The values and ethics are the following:

- The absolute value of human lives regardless of age or cognitive ability.
- Individualized approaches recognizing uniqueness.
- Understanding the world from the perspective of the service user.
- Providing a social environment that supports psychological needs.

Garrett (2009:63) has analyzed the data of his dissertation by following themes: *musical engagement, well-being, ill-being, and person-centered care*. I am going to approach the literature of this study by using this thematic division of four. To begin with, I am going to explain what a musician should know about dementia as a phenomenon and an experience, and later comment on the role of communication and interaction between a musician and an elderly person with dementia.

Dementia

Dementia is increasing as the population ages. In Europe, 5 million people are living with Alzheimer's disease. The worldwide number of Alzheimer's is 50 million (Zeisel, 2009). There are as many manifestations of dementia as there are persons with dementia, but adaptation to dementia usually follows the steps of grief, denial, anger, depression and acceptance. As dementia is a unique experience, the experience of dementia can be seen related to the different personality types (Alan Jacques, 1988): dependent, independent, paranoid, obsessive, hysterical, or psychopathic. The manifestation of dementia depends crucially on the quality of care and on the person's earlier developed psychological coping skills. All so-called problem behaviors should be viewed as a need or an attempt to communicate. Only understanding the needs can make them met.

Dementia has also been reported to have positive effects on a person, such as exceptional perceptivity, increased creativity and high emotional intelligence. Furthermore, it is important to understand that some specific types of memory last longer than others. For example, sense memories, emotional memories, body memories, art memories, song memories and skill memories usually last the longest. This is significant information for musicians working creatively with elderly with dementia.

The person-centered approach

According to the literature sources used for this study, the concept of person-centered approaches in elderly care involves:

- Understanding and caring for the unique personhood
- Understanding that dementia doesn't destroy personhood
- Building communication, relationships, supporting identity and meeting a person's psycho-socio-cognitive needs
- Aiming to reduce agitation, anxiety, apathy or aggression
- Increasing the quality of life and joy
- Helping people to maintain their dignity, independence and self-respect

Musical and Artistic Engagement

Zeisel (2009) writes that people with Alzheimer's are freer, more honest and more expressive than most others. Therefore they have an enormous capacity and potential for musical engagement. Rhythm and beat contain a message in themselves that is an effective form of communication.

Kitwood (1997), Garrett (2009) and Zeisel (2009) agree on the following statements:

- Music helps identifying emotions, telling stories, and linking them to people's own lives
- Music links together separate brain locations and activates the emotional memory
- The instinctual abilities of understanding music are not lost even when dementia is advanced
- Musical interaction promotes new relationships, quality of life, joy and increased self-esteem
- Music interventions ease depression, aggression and irritability

Well-being

"Despite of cognitive impairments, having a high level of well-being"

When interacting with people with dementia, the main goal is to support their individuality and maintained personhood. One needs to take into consideration the uniqueness of an individual's personal history: culture, gender, temperament, lifestyle, outlook, beliefs, values, interests.

People with memory impairments live in the present moment. That is their reality. Being present is the first step for promoting their well-being. Being in the present also has an existential dimension: breathing in, breathing out – existing. Therefore it is important to always respond to any attempt of communication in the present moment.

Promoting well-being also means appreciating the capabilities and abilities of the person, not focusing on the lost ones. In other words, it means seeing the person through the illness. It also has to do with the person's right to exercise their own choice, use functioning abilities and express their feelings.

An important part of well-being is to employ as many non-pharmacological treatments to the care as pharmaceutical ones. There needs to be a balance between the two types of treatments.

Recognizing psychological needs

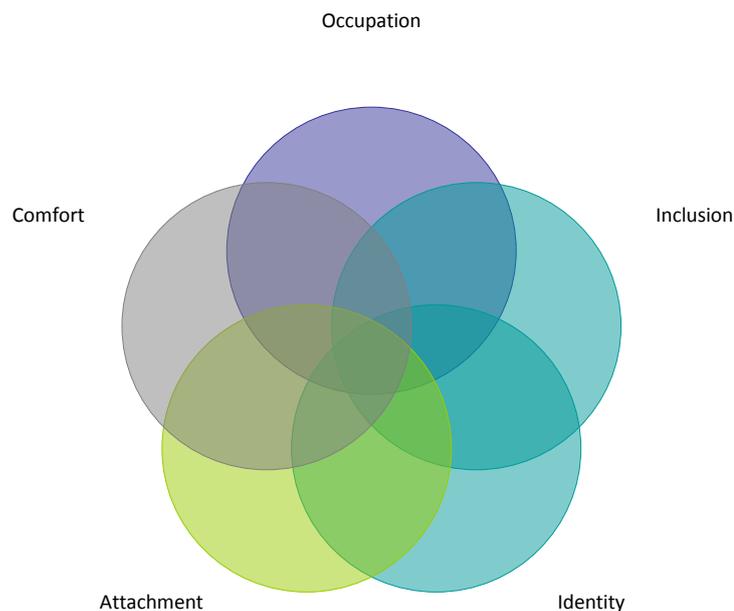
Kitwood (1997) refers to Gray-Davidson's choice of words when talking about the need for compassion and love of people with dementia: *"To give generous, forgiving, unconditional acceptance, a whole-hearted emotional giving without expectations"*.

The findings of this study suggest that the most significant psychological needs that people with dementia have are the following:

- *Comfort*: tenderness, closeness, calming and soothing, security, warmth
- *Attachment*: responding to the instinct-like needs of forming human bonds
- *Inclusion*: understanding the need to be part of a group, understanding “attention-seeking behavior”, clinging, protests etc.
- *Occupation*: helping to be involved in a process in a way that is personally significant
- *Identity*: supporting the cognition and feeling of knowing who one is

According to the source material, occupation includes the realization that it is possible to evoke a response in other people. Often occupation involves having some kind of project that might consist of play, such as music. Occupation has a relation to a person’s self-esteem. For a musician and a caretaker, skills and imagination are required for meeting the needs of occupation in a suitable way. The more is known about the person’s past and their desires, the more likely it is to find the right way of interaction.

Following Kitwood: Figure 5.2 (1997) for illustrating the central psychological needs of elderly people with dementia that should be met with empathy and love:



The art of Interaction

Under this title I have collected all the guidelines and suggestions by Kitwood (1997), Zeisel (2009) and Garrett (2009) on successful interaction and communication with people with dementia. As a point-of-

departure, it can be seen that the first task is to generate interaction and the second is to enable the interaction to continue.

Main points of the suggested forms of interaction are being present, being direct and clear, aiming towards creating a positive experience, being encouraging, facilitating the person, using all human senses, and including everyone individually in to the action. The most common mistakes in interaction can be seen as for example failing to recognize the attempts of interaction, being over-cognitive instead of sensitive, and either withdrawing too early from interaction or rushing it to happen. Other common problems relate to testing the person or treating like a child instead of a wholesome adult. Some dangers of interaction involve projecting own insecurities, fears, feelings and vulnerabilities on the person with dementia, or simply judging the person by their symptoms.

Here is a full list of guidelines that can be applied for a musician's work with people with dementia:

- Hear and respond to the other person's reality
- Be present, honest and calm
- Introduce yourself clearly and always address the person directly
- Use friendly body-language: smile, eye-contact
- Do as little as possible for a person
- Use all senses: also touch
- Find a person's unique way of self-expression
- Involve all participants
- Negotiate: ask and listen
- Collaborate: involve the person's abilities
- Play: encourage to self-expression
- Facilitate: enable to take part and try
- Validate: acknowledge the reality of a person's feelings
- Positivity: create a positive experience
- Ease anxiety
- Ask one question at a time
- Speak slowly and give time
- Watch for non-verbal expressions
- Let the person decide the topic of conversation
- Avoid slang, but use words that relate
- Don't test the person
- Don't say "don't", but redirect instead
- Don't react, but respond
- Don't approach the person in a child-like way
- Don't judge
- Don't project your own feelings or insecurities on the person

Ill-being

According to the literature of this study, people with dementia experience ill-being in different ways. Some experience situation-related feelings, such as fear, sense of weirdness, panic, grief, anger, sadness, anxiety, sense of being excluded or imprisoned. One can also experience general global states of terror, misery, rage or chaos. The permanent feelings of despair, depression, vegetation, exhaustion, apathy can also be seen as "burn-out" states of ill-being.

In Alzheimer's disease, there are four As related to ill-being: Apathy, Aggression, Agitation, Anxiety.

The Musician

Choosing the musicians for dementia-related work is a process where required qualities are examined. Such qualities are motivation, attitude, interaction skills and interpretation skills in non-verbal communication. One also is required to have empathy for the people with dementia as well as psychological stability needed for being in touch with their own fears, feelings, and insecurities.

Kitwood (1997) suggests role-play to help understanding dementia and/or meeting a person with dementia for a conversation. Also meeting someone, who has recovered from an illness with dementia-like symptoms, might help the musician to understand the experience of dementia. Moreover, observing the musician in these situations gives information about their qualification for the education program. Garrett (2009) has made observations on the recognizable effects working with people with dementia have on musicians on the Music for Life- organization. He has reported increase in confidence and sensitivity as well as changes in the relationships with the clients.

From the organizational point of view, support is needed for the musicians and care-givers in forms of debriefing, mentoring, counseling, two-way communication, stress-management and possibly psychologists. Kitwood (1997) has listed the needs of care-workers as following: induction, teambuilding, importance of team, supervision, training, psychological preparation, individual development, and reward.