“Music sets Things in Motion”

Music Therapy as Part of a Holistic Rehabilitation for People suffering from Chronic Obstructive Pulmonary Disease

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Master Thesis in Music Therapy

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To
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BREATHE FREELY

The air around is filled with you
You as you have been, you as you can be
The air inside you is filled with others
Strangers.

The air around you is filled with tones
Tones from a foreign time, tones from a distant future
The air inside you is filled with silence
Strange silence

So breathe freely
Breathe out the air filled with strange silence

So breathe freely
Breathe in the air filled with you and your tones
Of who you are and who you can be

-Sunniva Ulstein Kayser 2011-

Sammendrag

Musikkterapi som del av en helhetlig rehabilitering for mennesker rammet av KOLS

Antall mennesker som diagnostiseres med Kronisk Obstruktiv Lungesykdom (KOLS) har de siste årene økt kraftig og et underutviklet behandlingstilbud ansees å bidra til økt dødelighet. Gjennom nyere litteratur og forskningsfunn har et komplekst sykdomsbilde blitt avdekket og nødvendigheten av å utvikle en mer helhetlig rehabilitering har blitt understreket. Gjennom skildringer fra en person rammet av KOLS ønsket jeg å utforske hvordan musikkterapi kan ta del i en helhetlig rehabilitering for kolsrammede.

Musikkterapi med denne brukergruppen er et lite utforsket felt og kun kvantitative forskningsstudier har i skrivende stund blitt publisert. I et forsøk på å utvide kunnskapen omkring musikkterapi og KOLS, har denne studien blitt gjennomført innenfor en kvalitativ forskningstradisjon med bruk av *modifisert grounded theory* som metode. Tematikken har blitt utforsket i en tverrfaglig fokusgruppe med en brukerrepresentant. Det empiriske materialet har dannet grunnlaget for utviklingen av et teoretisk perspektiv.

Gjennom dataanalysen vokste det frem en utvidet forståelse av konseptet *helhetlig* knyttet opp mot en økologisk bevissthet omkring KOLS. Prosesser fremmet gjennom musikkterapeutiske tiltak ble ansett å stå i nær relasjon til denne forståelsen. Tverrfaglig samarbeid basert på gjensidige relasjoner mellom musikkterapeuten, personale og klient var imidlertid avgjørende for integrering og utvikling av musikkterapien i en helhetlig KOLS-rehabilitering.

Prescript

This master-thesis symbolises both the end of a period as a student and the beginning of my future as a music-therapist. I feel grateful and excited that music will be my wandering-fellow for many years ahead and hopefully spread joy, support, hope and growth for people.

Thanks to my mum and dad the gift of music was something I learned to appreciate at a very early age. It has followed me ever since, both as a friend and a support, but also as a challenger and, at a period of life, even an enemy. Still, I was always sure that music was something I wanted to have in my life for as long as I live. To share the gift of music with others is something I have always valued even more than wrapping up this gift myself. I have had several touching experiences of how music can be of help both for myself and for others when life is hard. A special person that I met early in my life introduced the use of music as a way to support others and inspired me to apply for music therapy. He is still and will always be a huge inspiration to me.

It is hard to describe in words the three years that followed after applying for the masters study of music therapy at the University of Bergen. It has been challenging, inspiring and very fun. Not at least has it been a huge development for me, both personally and professionally. That I was going to end up with a master-thesis about music therapy in COPD-rehabilitation was something that I could never have imagined when I started the course. Thus, the meeting with a woman with COPD at Bergen Red Cross Nursing Home autumn 2009 changed everything. Her story about how music therapy had helped her touched me deeply. I think that the reason why it made such an impression on me was because it resonated with the core of how I want to use music as a way to support others. I thereby owe this lady, who I have chosen to call Tove in my thesis, huge thanks. If it had not been for you, I would not have been able to walk this road together with so many incredible people when writing this master-thesis. Even so, if it had not been for the music therapist at Bergen Red Cross Nursing Home, Solgunn Elisabeth Knardal, this meeting with Tove had never happened. She is a highly skilful, talented and path-breaking music therapist who works hard and took responsibility for applying music therapy in clinical work with COPD-clients. To these two incredible ladies: I owe you my largest gratitude.

I also want to show my gratitude to the three people suffering from COPD that I was able to work with in music therapy last autumn 2010. You all taught me something about how it feels like to have COPD and I feel humble by your strength, your life-energy and your incredible humour. One of you also thought me to play the accordion and I promise I will keep on learning.

Huge thanks must also be given to my five informants in the focus group. Thank you for sharing of your wisdom and experiences, if it had not been for you this thesis could never have been written.

I also want to show my appreciation to my former supervisor, associate professor in music therapy Randi Rolvsjord who was the first person that supported me in writing about music therapy and COPD, and who has been a important support for me throughout the whole master-thesis process. Last, but not least I owe a huge gratitude to my master-thesis supervisor, music therapy associate professor Simon Gilbertson. Thank you for your ongoing support, patience and your belief in me and the thesis to become not just a master-thesis, but also something that could have a meaning for someone in the future. Thank you for never caring about the hours and for stating that your watch would be taken off every time we met. I hope that this will not be the last time we work together.

Sunniva Ulstein Kayser
Bergen, 14th May 2011.

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1. INTRODUCTION

1.1 Background and interest

The research-question for this qualitative master thesis is, "How can music therapy be part of holistic rehabilitation for people suffering from Chronic Obstructive Pulmonary Disease (COPD)?" The main reason for selecting this subject grew out of an empirical experience at Bergen Red Cross Nursing Home in autumn 2009. Here I met a woman, "Tove"[1], who suffered from COPD and received individual music therapy for half an hour each week. Tove spoke often about how music therapy had helped her to cope better with here everyday life, in her daily routines and with her relatives. On a physical level she felt that through vocal exercises and singing she was able to breathe better and she used the songs whenever she had problems breathing. Through the experience of having strategies for better breathing she felt more in control of the situation and this control significantly reduced her anxiety for getting suffocated when, for example, taking a shower. Because of this she was able to do more without the staff having to look after her**.** In researching the potential of singing upon anxiety and breathing, Bonhila & Onofre et.al (2009) discuss how singing might lead to better breathing coordination among COPD-clients and thereby reduce the anxiety that the authors claims are associated with unpleasant respiratory sensations (Bonhila & Onofre et.al., 2009). In Tove`s case, the reduced anxiety that she linked to music therapy, seemed to have a large impact on her everyday life. According to her descriptions, the main impact of music therapy was that her level of participation increased both at the nursing home and at home. One example of this was how she had started playing the piano again and used it when singing together with her grandchildren.

Tove described that the main reason why music therapy was of help was that it brought joy and happiness to her life and she was therefore very motivated to use her exercises and the singing at an every day level. It seems like the joyful experiences enhanced through music therapy created a spiral of positive development where the repeated use of the singing exercises, made her breath better and this further reduced her anxiety. This, in turn, contributed to an increase in agency in her everyday life and made it easier for her to participate. She also expressed that this had given her a improved life quality, a factor that is supported by literature whereby experiences of happiness seems to be closely related to life-quality, overall psychological well being and life satisfaction (Næss, 1994, Ferrans, 1996,Oleson, 1990, both referred in Schirm, 2002) As Næss (1994) states, the definition of life-quality seems to be based on peoples experiences of "activity, good interpersonal relations, self-confidence and a basic sense of happiness" (ibid, 1994, p.20, translated by Ruud, 1998).

[1] Anonymous name due to ethical concerns.

When considering that several COPD-clients suffer from depression (Kunik et.al.,2005) which correlates with increased mortality-rate (VanEde, Yzermans, Brouwer, 1999, Fan et.al, 2007) and low quality of life (Gore, Brophy & Greenstone, 2000, Ståhl et.al., 2003, Miravitlles et.al, 2004, referred in Miravitlles, 2007) the positive experiences of happiness outlined by Tove must be emphasized as a considerable source for increased life-quality[2] and possibly decrease in evolvement of the illness.

To see how music therapy addressed multiple layers of Tove's diagnosis was inspiring and formed the starting point the explorative process of how music therapy could be part of a holistic COPD-rehabilitation.

1.2 Disposition

During the research process a relationship between an ecological understanding and holistic rehabilitation for people suffering from COPD, began to emerge. In order to move towards an understanding of why such an approach might be advantageous for COPD, chapter two will begin with a presentation of COPD. This is followed by a literature review about the therapeutic use of music and music therapy with people suffering from COPD and other respiratory-related diseases. Combined with the literature upon COPD, this review has formed the background for the research question of this thesis. During the research process though some adjustments where made in the outline of this question and these will be discussed in chapter 2.3. Given the ecological perspective, holistic COPD-rehabilitation will also be contextualized on a social and political level and related to the term interdisciplinary collaboration. The discussion about holistic rehabilitation will then be contextualized in the music therapy-tradition.

In chapter 3, the choice of research-tradition, the overall method of modified grounded theory and the data-collection of focus group will be discussed and the research process will be described. Given the intentions of grounded theory's upon constructing theory from the empirical material, the empirical findings have thereby guided the selection of theoretical perspectives. Presenting the method before the theory, is therefore meant to illustrate the "real-life" research-process that developed when using modified grounded theory. The theoretical perspectives will be presented in chapter 4 followed by the empirical material in chapter 5.

[2] According to Schirm (2002), life-quality seems to be divided into two terms: general quality of life (QOL) and health specific health-related quality of life (HRQF). While QOL seems more related to socioeconomic demographic and life-style factors (Abeles, Gift & Ory, 1994, referred in Schirm, 2002) HQRF is more rapidly used in relation to chronic illness such as COPD (Schirm, 2002; Ståhl et.al., 2003) and are defined "(…)in relationship to health and physical function, emotional well-being, general health perception and role and social function" (Schrim, 2002) Thus life-quality in this thesis refers to health-related quality of life.

The empirical material will be combined with specific aspects from the theoretical perspectives discussed in chapter 4 in order to make explicit how the empirical material has guided the theory chosen.

The discussion-chapter (chapter 6) is separated into two parts, one discussing how music therapy can be integrated in holistic COPD-rehabilitation, while the second concerns how music therapy might contribute. The division of the parts is closely related to empirical findings. The empirical material and the theory will then be used in the concluding chapter (chapter 7) to construct a substantive theoretical perspective of how music therapy can take part in a holistic rehabilitation for people suffering from COPD. In this chapter critique of the research-process will be discussed and used to form the implications for further research.

2. CONCEPTS IN THE AREA OF INTEREST

2.1 Chronic Obstructive Pulmonary Disease (COPD)

According to the World Health Organization (WHO), COPD "(…) is a lung disease characterized by chronic obstruction of lung airflow that interferes with normal breathing and is not fully reversible" (WHO, 2011). The pulmonary disease[3] is categorized in 5 stages, from mild to highly critical and the rate at which the individual with COPD moves through the stages is related to correct medication, a well functioning treatment offer and in what degree the individual is able to take responsibility in their own treatment (Johannesen, 2003, 2007, 2009).

According to Gerardi and ZuWallack (2001), factors like nutrition, exercise, functional activity and social participation seem to play a crucial role in the development of the illness and a holistic approach will in their opinion directly contribute to decrease the numbers of deaths. Even so, it seems that the main focus of COPD rehabilitation to date has focused on reducing physical symptoms. This view is emphasized by Kunik et.al (2005) stating that psychological factors are insufficiently prioritized with patients with COPD. This bias is also present in Norway :

> We have to be honest to say that we in the medical fields have mainly been focusing on the pulmonary function of the COPD-patient. But it is reasonable to believe that factors like anxiety and depressions also contributes in the disease (Bakke, referred in Hanger, 2007, own translation)[4]

[3] According to Lubkin & Larsen (2002) disease refers to "(…) a problem that the practitioner views from the biomedical model" while illness "(…) is the human experience of symptoms and sufferings and refers to how the disease is perceived, lived with and responded by the individuals and their families"(ibid, 2002, p.4) The seperation between these terms (Lubkin & Larsen, 2002) will be used throughout the whole thesis.

[4] This statement is related to a research study at the University in Bergen in 2007, which focused on the psychological factors of the COPD-disease. The results of the study made it clear that the disease often leads to fatigue, lack of energy, social isolation and sleep interruptions. These are all factors that further on leads to anxiety and depressions among the COPD-patients (Nordhus, 2007, referred in Hanger, 2007).

This might point to the fact that COPD rehabilitation has put too much of a focus upon physical aspects of the disease. Even though there is a slowly growing attention upon COPD, it is, according to Global Initiatives for Chronic Obstructive Pulmonary Disease (2007), still a disease that is neglected by the public health department and the society in general. This notion is also supported by Gore, Brophy & Greenstone (2000) stating: "Chronic obstructive pulmonary disease (COPD) has been described as a major though neglected medical and social problem in the UK today" (ibid, 2000, p.1000). It is not easy to identify a satisfactory explanation for why the disease is neglected, given that public views must be seen in relation to the social context. One factor that might provide an explanation for this neglect is the contextual and ecological causes of COPD. Even though new research suggest that one of the causes for COPD may be related to biological and congenital factors (Pillai et.al, 2009), smoking and pollution still seems to be the main causes for explaining why people are diagnosed with COPD (Nasjonalt Folkehelseinstitutt, 2011) perceiving it as a self-inflicted disease. This view is supported by psychologist Dager (2009), claiming that the ignorance of the disease might as have been caused by social statements about the patients having themselves to blame for the disease because of cigarette smoking. The disease is therefore being classified as a "low-status disease" and public thoughts about the disease might therefore lead to the clients not being prioritized, which further affect the quality of the rehabilitation. As highlighted by Saylor, Yoder & Mann (2002) diseases perceived as self-inflicted also increases the stigmatizing effect both in the society, between the society and the person, and in the person themselves. These aspects might point towards a necessity for an ecological understanding of COPD, wherein the influences of environmental factors, such as the institution, the family, the community and society's impact upon the person and his illness, is taken into account (Bruscia, 1998). Thus the ecological theory of Bronfenbrenner that will be discussed more deeply in chapter 4.2. will be used as an overall theoretical frame both to understand the evolvement of COPD and for suggesting how music therapy can take part in such a approach.

2.2. Literature review

At the time of writing the amount of literature about music therapy and COPD is very small. Even though, there is some literature related to bio-psychological (Fried, 1990) psychological and medical perspectives (Lehrer et.al,1994) on the use of music with people suffering from different forms of respiration diseases. A large amount of the literature focuses on the effect of listening to music on anxiety and breathing patterns (Fried, 1990, Lehrer et.al, 1994). Other studies (Lehrer et.al, 1994) have explored the effect of music listening related to muscles relaxation. Wade`s study (2002) also incorporates "active" forms of music interventions for children with asthma. Through an experimental design music-assisted relaxation is compared with preference-based vocal singing[5].
The results show better effect of the last condition related to lung functioning and motivation (Wade, 2002). The correlations between motivation and better lung function, might indicate that when people are able to decide the music themselves, they are more engaged, and thereby more motivated to use the singing on a more frequent basis. This regular use of singing can further lead to improvement in physical factors such as lung function. As described with Tove (see chapter 1.1.), improvement in lung-function also increased her engagement and participation. This might imply a two-folded process of increased motivation through preference-based singing leading to better lung function that together resulted in increased participation.

A more active and self-determined use of music was also the focus in music therapist Engen`s study (2005) where she explored the effect of vocal exercises and preference-based singing in relation to physical health and wellbeing with 7 elderly with COPD. The effects were measured through quantitative measures and the results pointed towards the participants achieving of a more diaphragmatic breathing pattern[6]. The participants also showed a clear improvement in relation to the physical health, especially related to better pulmonary function and increased walking distance. The participants also reported that their life quality was improved in relation to mood and reduced feelings of loneliness (Engen, 2005). Engen`s research then draws some concrete lines towards how music therapy can be effective in addressing several factors in the life of COPD-clients. The main limitation of the Engen`s study is it's lack of a control group (Bonhila & Onofre et.al, 2009).

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[5] Prefererence-based vocal singing implies active use of the client's "musical preferences" which "(…) refers to the extent in which a person prefers, or likes, a particular kind of music over another" (e.g. Scherer & Zentner, 2001, referred in Rentfrow & McDonald, 2010,p.670). Personal traits, society and cultural background are suggested to be influential sources of the person`s musical preferences (Rentfrow & McDonald, 2010). In music therapy, using the clients musical preferences has formed the starting point for develop " the individualized-music method" (Gerdner,1997). Even though this is important method highlighting the potentials of preference-based music, its` indented population group (clients with dementia suffering from agitation) and its` specific procedure creates problems in contextualizing it relation to this thesis.

[6] Diaphragmatic breathing is a deep and healthy breathing-pattern that one attains when using the diaphragmatic muscles in the upper region of one stomach. According to Cleveland Clinic Health System (2009) this muscle is situated in the centre of the lungs, which makes it the most efficient muscles to use when breathing.

A control-group was thereby used in quantitative study by Bonhila & Onofre et.al (2009) that explored the effects of weekly singing classes on pulmonary function and quality of life (QoL) on COPD-patients. [7] The 30 participants, where randomized to either singing group or control group that did handcraft work. The result of the study showed that the singing group had achieved a significant higher respiratory capacity in comparison to the control group, both after short sessions of singing and at the end of the treatment. The effect on respiratory function was, according to Bonhila & Onofre et.al (2009) closely related to quality of life. "The present result (on higher respitatory rate, ed.note) suggest that singing classes could be a practical and pleasant way of training expiatory muscles (…) The engagement in regular pleasurable practice involving social interaction (…) has the potential to positively influence the attitudes and perceptions of these patients" (Bonhila & Onofre et.al, 2009, p. 6-7). The last statement could be generalized both to the control – and the singing group. Surprisingly, the research study did not present any concrete results of the QoL- measurement, it only mentioned that there was a trend towards higher QoL in the control group, but that it did not reach statistical significance.

The most important factor in the study of Bonila & Onofre et.al (2009) in relation to this thesis is that, by including a physiotherapist in carrying out the singing-group program, the authors highlight the potentials of interdisciplinary collaboration. In relation to this, two clinical music therapy examples that show the potentials and possibilities of collaboration work, where found. One portrayed the work of music therapist Alicia Clair, where she through collaboration with the physic therapist had experienced that patients with serious COPD, could increase their walking distance without needing more oxygen, when they listened to a guitar or singing (Clair, 2005, referred in Miller, 2005). The increased walking distance led to the fact that the patient was able to manage longer periods without the ventilator, an aspect that might be linked to increased freedom and independency, important to promote when working with people with COPD.

Another clinical example of interdisciplinary collaboration is "Music for AIR" (Advances in Respiration) at Louis Armstrong Music and Medicine Center at Beth Israel Medical Hospital. This program offers music-assisted relaxation and guided imagery, group music making and the "Sing-a-Lung chorus", thus combining the qualities from receptive and active use of music. The intentions of the program is to explore the advances in an integrative form of music therapy treatment for people with COPD (The Louis Armstrong Department of Music Therapy, 2006) and in the time of writing, the center is carrying out a qualitative study about these integrative advances.

[7] This study was performed by singing teachers .Thereby no music therapist was involved in the study. Even so, the study`s focus upon physical effects and quality of life through physical and vocal exerzises along combined with singing familiar songs in a group makes it a relevant study and meets the intentions of my focus on adressing multiple factors in the life of COPD-clients.

Based on literature, is seems that the music can have a significant meaning for people with COPD and other forms of respiration diseases. Even so, most of the literature illustrates quantitative studies for the documentation of these qualities. This might contribute to a relative effect-based and mechanical use of music, related to physical factors. Even though Engen (2005) and Bonhila & Onofre et.al (2009) focuses on the contribution of music in relation to psychological and psychosocial factors with people with COPD, the results are based on quantitative measures. These measurements might not able to capture the nuances of the participant's personal experiences of how music therapy can contribute to increase the life quality. Related to literature demonstrating the complexity of COPD and outlining the necessity to shift from a one-sided physical treatment towards a more holistic awareness wherein the user is involved (Gerardi and ZuWallack, 2001, Helse – og Omsorgsdepartementet, 2008, Raskin & Azoulay, 2009) research upon how music therapy can contribute in such a holistic manner is necessary. The literature-review combined with empirical experiences and literature upon COPD thereby shaped the direction of the research question upon how music therapy can be part of a holistic rehabilitation for people suffering from COPD.

2.3 The research question

The research question for this master thesis is, "How can Music Therapy be part of in a holistic rehabilitation for people suffering from COPD?" It is important to make explicit that during the research process it seemed advantageous to use the term "people suffering from COPD" instead of "COPD-patients". "A person suffering from COPD" then, is meant to imply that COPD is just one aspect of the person, rather than "a COPD-patient", which makes COPD function more as an "identity-marker" of the person. In addition, the term "treatment" where changed to "rehabilitation". This choice was mainly linked with a paradox that seems to exist within the medical tradition, related to how chronic illness is perceived and addressed (Lubkin & Larsen, 2002). According to Lubkin and Larsen (2002), the medical society rapidly uses the terms of medical "treatment" and "curing" in the context of chronic illness, which seems to be paradoxical, given the fact chronic illness by it's very nature never can be "cured". This has put chronic illness in a disadvantage, especially since professionals seem to be measuring some of their "success" in their ability able to "cure" their patients (Lubkin & Larsen, 2002). Thereby there is a need for a paradigm shift from addressing the chronic ill in a treating-manner of curing to one that focuses upon caring, regaining and maintain still preserved capacities (Lubkin & Larsen, 2002). This might point towards the term "rehabilitation", which is defined by the Worlds Health Organization (WHO) as follows: "Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels" (WHO, 2011).

Even though the definition of WHO is not written in the context of chronic illness, it seems to point towards some of the discussed aspect of a holistic and ecological view upon the person, through accounting for physical, psychological and social aspects. This view also seems to be dominating in several other definitions of rehabilitation. As Remsburg & Carson (2002) states: Most definitions emphasize the dynamic interaction among the individual and his or her personal characteristics, the disease or health condition, the environment, and the resulting impairment" (ibid, 2002, p.556). To develop a holistic rehabilitation-offer seems also to be a main aspects highlighted in the pulmonary rehabilitation of COPD: "pulmonary rehabilitation is defined as "a multidisciplinary program of care for patients with chronic respiratory impairment that is individually tailored and designed to optimize physical and social performance and autonomy" (Celli and Mac Nee**,** 2004, p.937) The latter aspects of autonomy is also found in WHO`s definition of rehabilitation through underlining this as a process giving the person tools to attain independence and self-determination (WHO, 2011).

On a general level, individual autonomy is described as one of our basic human needs along with relatedness and competence (Ryan & Deci, 2000). It is defined as "the ability of an individual to respond, react, or develop independently without outside control (Hummel, 2002, p.364). To contextualize it in relation to COPD, a strategy to increase client's control in their rehabilitation is to give the client knowledge to take responsibility in his own treatment (Johannesen ,2003,2007,2009). The latter aspect is seen as an important factor to decrease the speed of the illness-development (ibid.). A similar strategy is also outlined in the "Samhandlingsreformen" (Collaboration-reform, own translation) from the Norwegian Ministry of Health and Care Services (Helse- og Omsorgsdepartementet, 2008) where the importance of including clients in the development of the rehabilitation-program, is underlined.

2.3.1 Holistic rehabilitation in a social and political context

Since this thesis is about exploring how music therapy can take part in a holistic COPD rehabilitation through an ecological understanding of chronic illness, it is natural to situate the area of interest also on a social and political level, wherein holistic rehabilitation is receiving a growing attention. A qualitative study by Fugeli & Ingstad (2001) can be used to illustrate the social level. In their study, that explored people's concepts of health, 80 people in the age of 16-93 years from all over Norway, were asked about their associations to good health. One of six essential factors that were developed from the interviews was that health was looked at as a "holistic phenomenon" that is "interconnected with all aspects of society and life" (Fugeli & Ingstad, 2001, p.3600).

Even though these perceptions can not be proven significant for the general public, the large amount and range of people participating, creates a picture of a general holistic view on health, a view that might have direct consequences for how rehabilitation-offer are developed. If people in general see health as being interconnected with different factors in society and life, the treatment and rehabilitation offered to people should mirror these perceptions. Even though the traditional focus upon "curing" diseases is still evident in today's medical praxis (Lubkin & Larsen, 2002), a more holistic and ecological view of health is slowly influencing the healthcare services. As Hanser (2010) proposes:

> Healthcare services are slowly evolving from a disease and symptom model into one of prevention and wellness (…) Comprehensive medical centers are inviting practioners of non-medical disciplines to join their teams in an attempt to provide holistic treatment plans for patients (…) (Hanser, 2010, p.850).

This development might be linked with a growing focus upon activities that fosters health promotion that according to Ruud (2006) are linked with a more holistic perception of health. One of the reasons for this growing development might be related to the salutogentical perspective of the medical sociologist Aaron Antonovsky (1991). In contrast with the traditional pathogenic focus upon what makes us ill, the salutogenetical perspective focuses upon what makes us healthy. Several sources link this perspective with a notion of holistic health, among them Bringsèn, Andersson & Ejlertsson (2009) who propose shared aspects of the salutogenetic perspective, especially the sense-of-coherence concept[8] and a holistic health perspective. Ventegodt et.al. (2007) also links the salutogenetic perspective with a holistic health perception, giving the perspective meaning as, *"the healing of the whole patient's life"* (p.311). It must be made explicit that this was written in the context of a quantitative research-project upon psychodynamic short-term treatment with client who experience physical pain that could not be alleviated with medicine (Ventegodt et.al,2007). Still, when considering that the research was located at the "Research Clinic for Holistic Medicine" in Copenhagen, it might be used as an example for suggesting a link between the holistic health-perception and the salutogenetic perspective.

Even though a salutogenic perspective is important to consider for understanding the emerging holistic health-perception in the social and political society, a limitation for using the perspective as a main source with adult-population-group, such as COPD-client, is the difficulty of experience sense of coherence in adult life expressed in the perspective (Rolvsjord, 2008). In this thesis, the salutogenic perspective will thereby only be used as a source to take into consideration for understanding the development towards a more holistic health perception both in the general and the medical society.

[8] The "sense of coherence"- concept refers to the experience of meaning, coherence and a continuity of life and are seen as the core for creating resistance towards a disease in the salutogenic perspective (Antonovsky, 1991).

The growing focus upon holistic rehabilitation is also acknowledged on the political level in Norway as documented in "Samhandlingsreformen" (Collaboration-reform, own translation) (Helse- og Omsorgsdepartementet, 2008). In this report the Ministry of Health and Care Services stresses a holistic rehabilitation through claiming that better collaborations between different departments should be one of the most important development areas in health policy. COPD is used in this report as an example of a patient group, which because of the complexity of the disease, are dependent on collaboration in the health sector (Helse- og Omsorgsdepartementet, 2008). Celli & McNee (2004) also support the focus of collaboration for people with COPD in the so-called "integrated disease management for primary care in COPD" (p.943):

> Disease management can be regarded as an integrated and systematic approach in which healthcare providers work together in a coordinated and cooperative manner to produce an optimal outcome for a particular patient with COPD, throughout the entire continuum of care (Celli and McNee, 2004, p.943).

These aspect then points towards the necessity for developing an interdisciplinary collaboration in order for an holistic COPD-rehabilitation to be established. A perception of the meaning behind the concept of *interdisciplinary collaboration* seems thereby necessary.

2.3.2. Interdisciplinary collaboration

According to Oxford Dictionary, the term, "inter", as a prefix, is used to express the concepts "mutuality" and "reciprocally" (Oxford Dictionary, 2011). The result of combining the word "inter" with "discipline" which means "a branch of knowledge", (Oxford Dictionary, 2011) is the word "interdisciplinary" which is defined as "more than one branches of knowledge" (Oxford Dictionary, 2011). Combined with the meaning of the word "inter", interdisciplinary collaboration can be used to describe a reciprocal process of sharing and exchanging the different branches of knowledge that exist within a team. An awareness of the meaning behind the word "interdisciplinary" might thereby help the team to both share their knowledge reciprocally while at the same time promote mutual respect for each team member's uniqueness. By doing so, it might be easier to establish a shared ground from which the collaboration can develop. These last two concepts might seem oppositional to one another and it is therefore important to explicit the perception of "shared ground". Instead of perceiving the establishing of a shared ground as a search for similarities and commonalities between the team members, the team might look at it more as a "(…) part or portion of a larger amount (…) to which a number of people contribute" (Oxford Dictionary, 2011). The parts, or what could be called the ground-stones of the shared ground, should thereby constitute of each person's unique knowledge mutually acknowledged and reciprocally used in order to develop a holistic rehabilitation.

This perception of a team's collaboration, also seems to be the core of Brill`s (1976,referred in Twyford & Watson, 2008a) definition of a team: "A group of people each of whom posses particular expertise (…) who together hold a common purpose" (ibid.p.22,referred in Twyford & Watson, 2008a, p.13). An interdisciplinary collaboration model also seems advantageous in relation to the thesis overall focus upon holistic rehabilitation. As Remsburg and Carson (2002) points out: "As rehabilitation is a comprehensive process involving all aspects of an individual's life, an interdisciplinary team concept of care is essential (ibid, 2002, p.556).

To relate this discussion in the context of music therapy, working with other professions was crucial to the pioneers of music therapy in gaining support and acceptance, but also to educate and inform about the work of music therapist (Sutton,2008). In the last decades, the collaboration between music therapists and health-workers seems only to have increased on an international level (Aasgaard, 2006). These collaborations have led to new approaches that are of high profit for the patients in general (Aasgaard, 2006)

To work in an interdisciplinary team seems also to be advantageous for the music therapist to broaden his knowledge and make it easier to gain insight in to the overall rehabilitation goals (Twyford & Watson, 2008a, 2008b). Thus the music therapist might be better suited to work in accordance with these, while at the same time, be able to have an impact on the rehabilitation (Twyford & Watson, 2008a, 2008b).

2.3.3 Music Therapy in a holistic rehabilitation

In order to gain an understanding of how music therapy can contribute holistic rehabilitation for people suffering from COPD, an insight into the professions philosophical roots, history and clinical work is necessary. Stige (2008) traces the origins of music therapy as it was established in the American culture on the basis of WHO`s health definition in 1945, where the importance of seeing health in relation to physical, psychological and social aspects are highlighted (ibid, 2008). Music therapists working in the medical field in example with COPD-clients must then according to Bruscia (1998) deal with the psychosocial and ecological factors that might be affecting the bio-medical disease. In Norway, music therapy has strong links to the humanistic tradition, a relation that affect music therapists' perspectives on human beings and health in an ecological and contextual model. As Ruud (2008) outlines, a humanistic perspective is based on a multidimensional view of the human being which makes it necessary to account for the society, the culture and the systemic perspective wherein the client lives in the music therapy-sessions (ibid, 1998).

Even though this seems to propose an ecological dominance at least in the Norwegian music therapy-tradition, this might not be the total truth in "real-life". As Stige (2002) outlines: "A transactional and ecological perspective on development could be seen as a challenge to our concept of music therapy, which usually is seen as a microsystem phenomenon[9], connected to the relationship between a client and a therapist" (ibid, 2002, p.149). [10] This perception is also supported by Ruud (2008), which states that one of the weaknesses of music therapy is the small degree of reflection upon environmental and social aspect (p.10, own translation). Thus Stige developed an ecological music therapy approach influenced by among others by Bronfenbrenner (1979) wherein he stresses that the environment and the reciprocal interplay between the client and the environment should be taken into account in the music therapy (Stige, 2002). But Stige is not alone in fronting this type of view. According to Ruud (1998) Kenny brought system theory to music therapy in her book "The Field of Play" as early as in 1989, with Bruscia following some years later with the term "Ecological practice" (1998). One of the most significant people in Norway to use this approach both in clinical work and research are Aasgaard`s "Environmental music therapy" documented in his Ph.D (2002). It is also seen as one of the trademark of a resource-oriented music therapy approach. One of the founders of resource-oriented music therapy, Randi Rolvsjord (2008) points out that one of the essential factors about resource-oriented music therapy is that it emphasizes the interaction between the person and the society, a factor that is highly relevant in relation to seeing health as interconnected within life and society (Fugeli & Ingstad, 2001) and towards the ecological view outlined by Bruscia (1998). Even though this approach was originally developed in the mental health-context (Rolvsjord, 2010) the ecological awareness of the approach makes it advantageous to apply as an informing perspective also within the context of COPD-rehabilitation. This will be discussed further in chapter 4.4**.**

[9] The micro-system refers to "activities, roles and interpersonal relations experienced by the developing person in a given setting (…)" (Bronfenbrenner, 1979, p.22), in other words the setting in which the person lives and whom they can directly affect and be affected by.

[10] It must be made explicit that Stige`s statements is written in the context of children's` development.

3. METHOD

3.1 The search for a method

As discussed, the aim of this thesis is to explore how music therapy can take part in a holistic rehabilitation for people suffering from COPD. The main reason for situating the thesis in a qualitative research tradition is related to the literature review showing a narrow amount of qualitative research upon music therapy with COPD and the necessity for a more holistic rehabilitation-offer for people suffering from COPD. The close relationship that seems to exist between holistic rehabilitation and an ecological approach wherein awareness of the social and cultural impact upon COPD, seems also to make qualitative research an advantageous method to apply. As Malterud (2008) outlines:

> If we want to look at illness and health as dynamic processes in the living human body, we do not only need generalized knowledge. We also need scientific approaches that acknowledge that these types of processes are formed specifically by each human being, located in a socio-cultural context. Qualitative methods of research can open up some possibilities for scientific insights into these types of processes (Malterud, 2008, p.32, own translation).

The need for qualitative research in the field of COPD and music therapy is also related to the increasing amount of literature stressing the importance of a type of rehabilitation and knowledge that highlights the complex and multilevel impact of COPD on a person (Gerardi & ZuWallack, 2001, Celli & McNee,2004, Kunik et.al.,2005, Bakke, referred in Hanger, 2007, Helse- og Omsorgsdepartementet, 2008). When considering that qualitative research seems advantageous to use in order to capture the differences and nuances of people's lived experiences (Ashworth, 2008, Malterud, 2008) the knowledge constructed might be used to describe the experiences of both living with and working together with a person suffering from COPD. This qualitative study can thereby be seen as having two main intentions. One is to try and increase the knowledge about how music therapy might contribute to people with COPD, while the other is to try and make a contribution to broaden the rehabilitation offered to COPD-clients by exploring how music therapy can take part in a holistic rehabilitation.

The focus upon holistic rehabilitation through collaboration also demands that the knowledge is constructed through focus-group discussions between several professions and a COPD-representative in a focus group. In relation to the literature review, the social and interactional context that is facilitated through focus groups can promote the creation of new ideas and of looking at topic from different angles (Robson, 2002). The qualities of a focus group then might increase the possibilities for generating a rich and broad knowledge about the area of interest. To include a COPD-representative in the research was also based on the Ministry of Health and Care Services focus upon integration of the clients in the development of their own rehabilitation-offer (Helse- og Omsorgsdepartementet, 2008).

The choice of research participants can thereby be said to have had a clear relation to my area of interest, a factor that in the literature often is labeled as "strategic or purposeful sampling" (Malterud, 2008).

After deciding to use focus group as data-collection, I searched for an overall method that would allow the "lived" experiences and discussion of the focus group to become the ground stones and guide the constructing of knowledge about how music therapy could take part in a holistic COPD-rehabilitation. Related to the thesis focus upon user-involvement, I first saw it as advantageous to use action-research as the overall method. Still, related to the fact that the knowledge constructed for this thesis would be based on discussions between several disciplines rather than only COPD-representatives could be considered a fraction in relation to action research's main intentions of the user-perspective as the basis for constructing knowledge (Stige, 2002; 2005, Reason & Riley, 2008). I thereby decided to use grounded theory (Glaser & Strauss, 1967) originally constructed as whole method for "discovering theory from data" (p.1) as a reaction against the positivist-paradigm of both quantitative and qualitative research on verifying existing theories (ibid, 1967). Glaser and Strauss's intention was also to give qualitative researchers a more systematic method for analyzing the data, thereby making an attempt to strengthen the status of the qualitative research tradition.

The data-analysis of grounded theory is outlined as a constant comparing and alternation between the data-analysis and the data-collection wherein the researcher through a set of coding procedures moves from a broad, open and flexible data-collection towards a more narrowly focus related to emerging themes in order to generate a theory that should "fit" and be "understandable" to the area researched (Glaser & Strauss, 1967, p30, Strauss & Corbin, 1990,p.23). Through this data-analysis-process two types of theories can be generated; *substantive* and *formal*. A substantive theory is related to the concrete empirical area being studied, such as in this thesis, while a formal theory is one that is developed for a more conceptual area or can be generalized to several arenas. A substantive theory can be transformed into a formal theory by collecting data from different sites in relation to the same topic (Glaser and Strauss, 1967). One of the main intentions of the theories generated and the method in general is upon "understanding the action in a substantive area from the point of view of the actors involved" (Glaser, 1998, p.115). In addition, it is viewed as method particularly useful in fields where pre-existing theories are few (Robson, 2002). This is also one of the qualities of focus group wherein in literature it has been stated that it is advantageous to use as a method for data-collection when unfamiliar or new areas or fields are to be explored (Stewart, Shamdasani & Rook, 2007, Malterud, 2008, Wilkinson, 2008). Related to this thesis, to use focus group as the method for data-collection and grounded theory as an overall method for interpreting the data was closely related to the intentions of generating substantive knowledge that could mirror the individuals' multitude experiences and

knowledge. This substantive knowledge could then be used as a ground stone for broadening the insight about how music therapy could be integrated in a holistic COPD-rehabilitation and how the profession could take part and contribute in the growing social and political focus upon holistic rehabilitation.

Glaser and Strauss (1967) state that grounded theory is advantageous for generating "(…) better theories for areas where previous ones do not work" (ibid, 1967, p.11). It is important to clarify that the use of this statement is not indented for implying that qualitative theory is better than quantitative theory for this group; we need both to make it better. In the terms of grounded theory methodology; we need theory that *fit* the multi-componential reality in which people with COPD live so that the theory is *useable* both to themselves, their relatives and the persons working together with them. [11] Thereby we also need theories that are generated on the experiences and knowledge of the persons in the area and are able to capture different components of their living reality. In that way we can use the qualities from both quantitative and qualitative research to begin constructing integral and multilevel theories that the people involved can use.

It must be made explicit that grounded theory have been modernized and modified during the years by additional researchers. This is especially true for Strauss who in 1987 took a new stance, naming grounded theory a particular style of qualitative data-analysis rather than a whole method (Strauss,1987). In the later years several researchers chooses to perform so-called modified grounded theory which according to Amir (2005) implies that the researcher does not follow every detail of the method or do not create a full theory (ibid, 2005, p.370). In the context of this research-process, even though the coding procedures of grounded theory were followed and a core-category did emerge, limitations in relations to time, lack of research-experiences and amount of data collected created a challenge in generating a substantive theory. It is thereby naturally to consider the study as a modified grounded theory-research.

[11] The reason why I have highlighted the word "fit" and "useable" is because they are two of four main criteria's that judges the theories practical applicability (Glaser & Strauss, 1967, Strauss & Corbin, 1990).

3.1.1 Grounded theory in music therapy research

According to Amir (2005) music therapy researchers have used grounded theory method both in a complete form (i.e. Nagler, 1993, Ruud, 1997) and modified version (O´Callaghan, 1996, Edwards & Kennedy, 2004, Kwan, 2010). The intentions and reasons for using grounded theory in music therapy though seem to vary. Daveson, O`Callaghan & Grocke (2008) suggest that grounded theory can be used in music therapy research for generating indigenous music therapy theory that explains the lived experience of music therapist and/or clients (Daveson, O`Callaghan & Grocke, 2008). It can also be applied as in with Edwards & Kennedy (2004)[12] in the development of music therapy practice and research in rehabilitation-services new to music therapy practices (ibid, 2004). As a result this research contributed to the development of music therapy practice and research in music therapy in the field of study, namely children's pediatric rehabilitation (Amir, 2005). Even though this research project was outlined in another context than the research-project of this thesis, Edward and Kennedy's intentions for using grounded theory seems to have close parallels to the intentions of applying the method to this thesis.

3.2 The research process

The research process has followed the general outlines of a grounded theory study (Glaser & Strauss, 1967, Strauss & Corbin, 1990;1998) and ethical concerns outlined by Dileo (2000;2005). In an effort to clarify the reserach process, a ranked overview of it`s progression will be given before presenting the process in detail.

1. Identification of topic and research question
2. Reviewing the literature
3. Identification of appropriate method
4. Choice of research-venue, "Bergen Red Cross Nursing Home"
5. Ethical clearance with REK
6. Purposeful sampling of focus group participants. Informed consent given to each participant.
7. Construction of interview-guide number 1.
8. Focus group interview 1: Audio-taped and fully transcribed. Transcription analyzed through open coding. Identification of concepts and properties.
9. Construction of interview-guide number 2.
10. Focus group interview 2: Audio-taped and fully transcribed. Transcription analyzed and concepts identified. Combining of concepts into categories through axial coding.
11. Construction of interview-guide number 3.

[12] The origins of this source is Edwards P.h.D-project from 2000.

12. Focus group interview 3: Audio-taped and selectively transcribed. Transcriptions analyzed and categories grouped into main categories through selective coding. Core category identified.

3.2.1 Ethical clearance and purposeful sampling

After identifying the topic, the research question and the method, an application for ethical clearance was sent to *The Regional Committees for Medical and Health-related Research Ethics (REK).* The REK committee concluded that the research did not need full ethical clearance due to the intended role of the participants speaking on behalf of their professional-roles and the COPD-representative speaking on behalf of the COPD-population, rather than as a private person. Participants were thereby sampled in a dialogue with one of the chief-nurse at Bergen Red Cross Nursing Home wherein the research took place. [13].

The main criteria for choosing participants were first of all that they had experience and/or knowledge with COPD. For the COPD –representative a main criteria was that his or her medical record showed that the person had COPD. The second criteria were the capacity to participate, related to the COPD-patients' actual state of health and the staff's working schedule. The criteria led to an elimination of the nurse participation and a sudden change in doctor-representative the day before the first interview. Though informed about the study, the new doctor-representative did not receive the informed consent prior to the interview.

The group finally consisted of a COPD-representative, a doctor, an auxiliary nurse, a physiotherapist and a music therapist. All individuals were asked personally about participating and were given oral and written information through an informed consent about the background and intentions for the study. Except from the doctor-representative, this procedure was accomplished three weeks before the first focus group interview in order to secure that the participants where fully informed about the study (Dileo, 2005). Thus, the late information to the doctor might have caused a limitation in ethical concerns and affected her participation especially at the first interview**.** This is also related to the possibilities for affecting the time and date for the first focus group interview for which the other participants was given a possibility to affect at the meeting three weeks before [14].

[13] The collaboration- sampling of participants with the chief-nurse was especially important in relation to the choice of COPD-representative. This was both related to his capacity and his already established relationship with me in my music therapy practicum. By the fact that I had two COPD-clients in my practicum-period, to let the chief-nurse decide which one should participate was a way to reduce the risk of personal bias of me choosing between the two clients. A limitation of this choice is that only one of the COPD-clients was admitted at the department where she was chief-nurse Her familiarity with the patient then might have guided her choice. Even so, the other client staying at the department under was a man that refused to leave his room. To ask him to participate in the study, wherein he had to be moved to another side of the building and sit there for one hour was seen as unethical.

[14] Since the timing for the first meeting was not appropriate for some of the professions and for the COPD-representative in relation to his daily routines, I used the end of each meeting to set up the time for the next meeting in a dialogue with all the participants.

3.2.2 Data-collection and analysis

In an effort to work in accordance with the process of data-collection outlined in grounded theory whereby the researcher moves from an open towards a more narrow focus, a semi-structured interview style was chosen. Within this interview style, an interview-guide is constructed and designed to give the participants an amount of flexibility to bring up topics that the interviewer did not think of (Smith & Osborn, 2008). Before the first interview I tried to construct questions that facilitated a wide exploration of the area of interest. The participant's explorations during the one-hour meeting thereby formed the starting point for the coding procedures and guided the construction of the interview guide for the next interview for which more specific questions were constructed related to the emerging themes**.** [15] In relation to grounded theory's overall intentions of not "forcing" the data into existing theories (Glaser & Strauss, 1967) no external theory was read during the data-collection and analysis. The theories generated in the thesis have thereby been guided by the emerging themes and categories in the empirical material.

All the interviews where audio-taped, transcribed and analyzed between each focus group meeting. The analysis between each interview guided the focus for the next meeting. The first and second interviews were fully transcribed in order to understand patterns of how the focus group's interaction shaped the emerging of themes. This insight made it easier to recognize patterns and themes in the last interview, which thereby were selective transcribed. A transcription process that moves from broad and fully transcriptions to narrow and selective ones related to the emerging of themes is also supported by literature (Glaser & Strauss, 1967, Strauss & Corbin, 1990). After each transcribing, I read through it while listening to the recordings to reduce the changes for misinterpretations. In line with Strauss and Corbin's data-analysis strategies (1990), I then read through it without listening to the recordings before starting to analyze it. After the first reading, I took some time to write down my thoughts and comments about the interview. When starting to code the interviews then, I could compare the interpretations with these notations to see if the interpretations were rooted in my own thoughts or within the data-material itself. This was done in order to decrease the effects of personal bias.

The first focus group interview was analyzed using open coding which is concerned with "(…) the process of breaking down, examining, comparing, conceptualizing, and categorizing data" (Strauss & Corbin, 1990, p.61) and enables the researcher to use the data-material to develop "(…) categories that capture the fullness of the experience and actions studied." (Kvale & Brinkmann,2009, p.202). It must be made explicit that during the first data-analysis, only concepts were constructed.

[15] This process was also repeated between the second and the third interview.

Within each concept I used statement-examples from the interview to increase the chances for the concepts to be "rooted" in the actual words of the participants reflecting the inductive approach to the data-material (Strauss & Corbin, 1990, Amir, 2005). This procedure was done throughout the whole research process. Similar concepts were then grouped and formed the basis for constructing of the interview guide for next focus group meeting.

After transcribing and reading the second focus group interview I coded it using both the concepts found in the first interview and constructed new ones for the statements that did not fit with the first concepts. This was done in order to reduce the chances of "forcing" the statement into already constructed concepts. I then compared the concepts and their related statements in the transcribed material from the first and the second interview and paired similar concepts from the two interviews together. In grounded theory, this process is defined as "the constant comparative method of analysis" (Strauss & Corbin, 1990, p.62) and general rule for is that "(…) while coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the same category" (Glaser & Strauss, 1967, p.106). The comparison then formed the basis for grouping the concepts into categories and for grouping similar categories together, a coding-process which in literature is defined as axial coding: "A set of procedures whereby the data are put back together in new ways after open coding by making comparisons between the categories" (Strauss & Corbin, 1990, p.96).

Through comparing each incident, concepts and statements within each category, I was also able to generate more and more theoretical properties of the categories (Glaser & Strauss, 1967). The categories emerging should also consist of properties[16], which in my analysis mainly were constructed through re-naming the concepts. This was done in to build a theory with each level of the building process being tightly interwoven with one another.

At this stage of the analysis, some themes stood out as particularly important because they were discussed at several occasions in the first and second interview. To make sure that the repetition of the themes were not only rooted in my own perceptions, I constructed the interview-guide for the last meeting with direct follow-up questions from the former interview and "summing-up questions" that made it easier to check whether the perception of emerging themes was presented in the data-material.

16 Properties are defines as "(…) conceptual aspects or elements of a category" (Glaser & Strauss, 1967, p.36).

After the last interview was transcribed, all the transcripts were read through again. Categories that were seen in all interviews were grouped together in the final stage of coding known as "selective coding". Here the researcher ascertains that no new aspects, insights and interpretations are appearing from the coding which identifies the point of so-called "theoretical saturation"[17] (Glaser & Strauss, 1967, Strauss & Corbin,1990, Kvale & Brinkmann, 2009) and a core category emerges. In the literature, this category is seen as "the central phenomenon around which all the other categories are integrated" (Strauss & Corbin, 1990, p.116). In my case, this core-category emerged after an immersed period of analyzing, writing and supervisorial discussions.

3.3 Trustworthiness of the study

3.3.1 Validity

Several strategies were used to ensure internal and external validity of the data analysis and result. For increasing internal validity I had a close and ongoing contact with all of the participants through e-mail and personal information exchange. At each interview, I handed out the transcribed material and my ongoing analysis from the former interviews to the informants to check whether or not the meanings perceived in the data where congruent with the participants' meaning of the statements, often named *informant verification* (Goetz & LeCompte, 1984) in the qualitative research tradition. This allowed me to check whether or not the emerging categories where rooted in the area researched or based on my own assumptions. I also let the data-analysis between each data collection function as the ground-stone for the construction of the next interview-guide. In relation to the potential risks of biases this ongoing alternation between the data collection and data-analyzes is seen as a strategy for reducing bias (Strauss & Corbin, 1990).

When constructing the concepts, properties and categories, the participants' wordings were used on several occasions, an alternative also outlined by Glaser & Strauss (1967), which they later defined as *"in vivo" codes* (Glaser, 1978,p.70, Strauss, 1987, p.33) Based on the participant's knowledge and experiences, their wordings seemed to be more applicable to describe features' in relation to COPD and music therapy, than those consisting in my own vocabulary. To use the participants' own wording then might thereby increase the validity of the categories which thereby increase the changes for constructing a theory that are grounded in the area[18].

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[17] In my own data-analysis, I felt it was natural to look at this saturation in a moderated form related to the limitations of the data-material only coming from one group of participants and in relation to the time-aspects of this thesis. This demand of theoretical saturation has also been a target for critique and a revised definition was made by Strauss & Corbin (1998). Here they stated that theoretical saturation is only reached to a matter of degree.

[18] It is important to underline that the translation-process of the participant's statement from Norwegian to English might have modified the originally meaning of the participants statement. In order to reduce the changes for this, the participants were given the translated version and a constant comparison between the Norwegian and the English meaning and interpretation of the words has been performed during the translation process.

In relation to external validity, I had regular meetings with my supervisor before, between and after the meetings, where we discussed the findings, the grouping of concepts and categories and the construction of interview-guide between each meeting. A possible weakness of this external validity strategy is related to fact that the transcriptions of the interviews were in Norwegian and my supervisor is an English language speaker. To increase external validity and avoid bias of language distortion then, I triangulated my findings through presenting my data-material at a master thesis-seminar, and through consultations with a Norwegian music therapy-professor at the University. I also handed out my final result to the focus group participants and gave them a translated version of the statements used in the data chapter of this thesis.

3.3.2 Theoretical sensitivity and reflexivity

In the context of this master-thesis, the fact that the area of interest grew out of empirical experiences clearly points to the fact that my personal interest and background might have been a component affecting the research process. Throughout the research process, I used my personal interest as strength to identify meanings and importance topics in the data. At the same time, I have been very aware of how it could create bias and thereby reduce the trustworthiness of the generated theory (Strauss & Corbin, 1990). To avoid the dangers of bias, I used the strategies outlined by Strauss & Corbin (1990), asking questions such as "does what I think I see fit the reality of the data?" (p.44) and maintained an attitude of skepticism toward theoretical explanations throughout the whole research process (ibid, 1990). The latter strategy of bias reduction forced me to ask whether or not my explanations and categories came directly from the data or from other sources such as external theory read before the research-process, personal experiences with Tove and in my ongoing practicum with the COPD-representative. These are all sources of theoretical sensitivity (Glaser & Strauss, 1967, Strauss & Corbin, 1990), a term that stands in close relation to *reflexivity* describing the necessity to make explicit ones background and interest in the researched area to increase validity (Yardley, 2008). It was thereby extremely important to remember the following rule, "(…) any theoretical explanations or categories brought to the research situation are considered provisional until supported by actual data" (Strauss & Corbin, 1990, p.45). Since my intention was to generate a substantive theoretical perspective, the context wherein the data was collected, transcribed, analyzed and generated was also an important factor to take into account in the interpretation of the empirical material (Glaser & Strauss, 1967).

3.4 Ethical concerns

The main source informing and influencing both the outline of the informed consent and the whole research process, where the two main ethical principles in research outlined by Dileo (2005). The first is genuine respect for those who participate while the other one relates to the fact that the research's advantages should outweigh the disadvantages (ibid, 2005). The respect for those who participate was considered especially important by the fact that the focus group consisted of people with different knowledge and experience. A possible risk foreseen was that the COPD-representative could feel that his knowledge was limited compared with, for example, the doctor's knowledge. A concrete way of trying to avoid this was to stress the importance of every participant's presence in relation to the research project (Stewart, Shamdasani & Rook, 2007) and try and create a safe environment for the participants to share their knowledge and experience.

In the informed consent complete information about the study, both in relation to advantages and disadvantages, the choice of confidentiality[19] and voluntary participation, were described. The reason why I highlighted voluntary participation was related to the fact that the participants might have felt a pressure of having to help me complete the study, as it should end up as my master thesis. The emphasis of voluntary participation was also related to the fact that the COPD-representative was one of my clients in the music therapy-practicum. This is a fact that might affect the client-therapist relationship, in example through the client feeling that his willingness to participate and not at least, to withdraw from the study, might affect the relationship in music therapy (Bruscia, 1995a;1995b, Dileo, 2000; 2005). When asking the client to participate I told him that our relationship in the music therapy sessions would not be affected by his participation and possible withdraw from the study. I also made a conscious choice to wait until the end of our sessions to give information that were related to the study to reduce the chances of our sessions being affected by this information. Related to his participation in the focus group I underlined that his role was seen as a spokesman for the COPD-population, not as a private person. This was done to reduce the pressure of him feeling that he had to share personal information and thoughts to the rest of the participants.[20]

[19] Even though Dileo (2005) underlines that guaranteed confidentiality should be given to the participants in the consent, due to the nature of this study wherein the focus group interviews focuses on the informants professional role to, the degree of confidentiality were decided together with the participants. At the first meeting the participants chose full confidentiality and this decision was kept throughout the whole process. Thereby only codes for showing the profession are used in the empirical material. In relation to the COPD-representative, full confidentiality was decided beforehand.

[20] It must be made explicit though that during the interviews the COPD- representative at several occasions experienced shortness of breath and coughing that seemed to cause problems in his ability to speak up and to concentrate on general topics. To increase his opportunity to participate, I asked him direct follow-up questions related to his statement. I also at some occasions suggested that he might relate general questions to his experiences of the music therapy sessions or his musical past. Even though this could be seen as a break in the focus upon the general nature of this study and facilitate a feeling of including our music therapy sessions in the study, I felt that it was necessary to do sometimes in order to increase his participation in the focus group.

In the informed consent the possible disadvantages and risk in participating in the study was also highlighted (Dileo, 2005). Related to the patient-representative, the risks outlined was related to physical disadvantages such as shortness in breath as a result of ongoing discussions and psychological stress by possibly sharing personal thoughts related to his own disease. I thereby suggested that he could bring with him his respirator in an attempt to reduce the physical malaise. In order to try and reduce the psychological stress, the participants and the researcher's respect for his possibly sharing of personal thoughts, where highlighted. The biggest disadvantages for the professions participating, where related to the fact that that the focus group might become an extra burden and stressful factor in their work (Dileo, 2005). The time and date for the focus group meetings where thereby agreed through a dialogue with all the participants.

In an attempt to outweigh the disadvantages (Dileo, 2005), possible personal, social and scientific advantages of participating were highlighted in the informed consent. Desirable advantages of my research project, was that the participation would contribute to increase personal and professional knowledge through interaction with other profession areas. Further, my hope was that this interaction could contribute to create a social network that could positively affect the development of interdisciplinary collaboration.[21] Related to scientific advantages, my wish was that the result of the study, based on the participant's knowledge-development, could contribute in the development of a more holistic rehabilitation for persons suffering from COPD, wherein music therapy can take part.

4. THEORY

As discussed in chapter 2.1, a necessity for understanding and addressing COPD in a holistic an ecological manner related to the complex nature of the disease, is outlined through empirical experiences, clinical work and literature (Gerardi and ZuWallack, 2001, Bakke, referred to in Hanger, 2007). The small amount of literature upon music therapy and COPD creates a necessity to broaden the knowledge about how music therapy can contribute on holistic COPD-rehabilitation. In line with these factors, it seemed advantageous to use aspects from a resource-oriented music therapy approach especially related to the approach's awareness of the society and culture that the client is part of (Rolvsjord, 2004; 2008; 2010). Before discussing this approach though, it is important to construct a theoretical frame based on ecological perspectives (e.g. Bronfenbrenner, 1979) and literature on the impact of chronic illness on social and personal identity. The intensions of this frame is to develope an understanding of how a chronic illness such as COPD might affect the person's identity and the society's perception of him in a holistic and ecological manner.

[21] In the empirical material statements that might be linked with these advantages were in fact stated both by the auxiliary nurse, the doctor, the music therapist and the physio-therapist who actually began discussing the possibilities for collaborating together to establish a music-group for COPD-clients at the end of the second meeting.

To gain an insight into these processes might make it easier to understand what a resource-oriented music therapy approach might contribute with in relation to COPD-clients.

4.1. Towards a holistic and ecological understanding of COPD

Chronic illness, such as COPD, can have a large impact in a person's life in relation to physical, psychological and psychosocial factors. Chronic diseases may reduce people's independency in relation to their daily life, and to the level of social participation, affecting the social network around the person. As Lubkin & Larsen (1998) propose, "Confirmation of a chronic condition affects the social, psychological, physical, and economic aspects of a person's life, often in a cyclic manner" (ibid, 1998 p.8). In the context of COPD, the manner of how the illness affects the life of a person seems to be linked not only to physical symptom, but also ecological and contextual factors, thus outlining the necessity for integrating an ecological approach in the holistic rehabilitation.

This integration might not be the most difficult considering the close relationship that seems to exist between an ecological approach and holistic rehabilitation. In the medical context the word "holistic" refers to "the treatment of the whole person, taking into account mental and social factors, rather than just the symptoms of a disease" (Oxford Dictionary, 2011). To take into account, especially the social factors might imply the need to take into account the culture and society wherein the person lives in the rehabilitation, which clearly points towards an ecological perspective upon illness as outlined by Bruscia (1998). This perception can also be linked to the philosophic use of the word "holistic" that relates to a belief that the parts of something are intimately interconnected and explicable (Oxford Dictionary, 2011). This philosophical use of the term holistic and it's relation to an ecological perspective is used both by Bronfenbrenner (1979) ecological development theory, in social science by Bateson (1973) and in Von Bertalanffy`s general system theory (1950). The latter theory was developed at a time when the tradition of natural science dominated and the focus was upon researching isolated parts. In a growing focus upon the relationship between the parts, it was thereby necessary to develop theories that could contribute with a holistic picture of the parts as interconnected with one another (Von Bertalanffy, 1950). While Von Bertalanffy (1950) seems to be using mathematic formulas for explaining how these parts interconnect with one another both in biological, machinery and social systems, Bronfennbrenner`s ecological theory (1979) written in the context of psychology, focuses more on the social processes of reciprocal interaction between the individual's biological armament and the environmental factors in the developing individual (Wormnes & Manger, 2005, p.13, own translation). In the context of this thesis, COPD as a disease can be viewed as a type of biological armament impacting the person's capacity and overall identity. Even so, the environmental, ecological factors is also impacting the development of the illness, making it necessary to see all the influencing parts as inter-relating with one another, creating a holistic understanding of the development of the illness.

Bronfenbrenner`s work on the "Ecology of human development" (1979) thereby seemed to be advantageous to apply as a ground stone for understanding the ecological and holistic impact of COPD. Before situating this theory in the context of COPD- rehabilitation, an insight into the systemic processes of this theory is necessary.

4.2 Urie Bronfenbrenner´s ecological theory

Bronfenbrenner`s theory was inspired both by Kurt Lewin`s theoretical emphasis on close interconnection between the structure of the person and the situation (1935) and Jean Piaget`s book, "The construction of reality in the child" from 1954. Bronfenbrenner took this further, not only defining the building blocks in the environmental aspects, but looking upon how "(…) these entities are related to each other and to the course of development" (Bronfenbrenner, 1979, p.11). The intentions of Bronfenbrenner was to construct a theory that:

> (…) seeks to provide a unified but highly differentiated conceptual scheme for describing and interrelating structures and processes in both the immediate and more remote environment as it shapes the course of human development throughout the life span (Bronfenbrenner, 1979, p.11). [22]

The ecological environment is looked upon as a set of nested structures, with one being the core of the next, affecting and re-affecting each other. Bronfenbrenner (1979) defined these structures as micro-, meso- and exo- and macrosystems. The micro-system refers to "activities, roles and interpersonal relations experienced by the developing person in a given setting (…)" (Bronfenbrenner, 1979, p.22), in other words the setting in which the person lives and whom they can directly affect and be affected by. "Meso" refers to "(…) the interrelations among two or more setting in which the developing person actively participates (…)" (ibid, 1979, p.22) for an example the rehabilitation-centre and the home of the COPD-client. "Exo" is defines as "(…) one or more settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the developing person" (ibid, 1979, p.25). An example related to people with COPD, might be that their spouse retires from work, thereby having more capacities to support them and making it possible for the COPD-client to spend more time at home. The last system is the macro-system which refers to the culture in which the person lives, in other words the "consistencies, in the form and content of lower order system (…) that exist, or could exist, at the level of the subculture or the culture as a whole, along with any belief systems or ideology underlying such consistencies" (Bronfenbrenner, 1979, p.26).

[22] It is important to make explicit that Bronfenbrenner's ecological theory was written in the context of children-development. Even so, his notion upon the ecological systems as something having an impact throughout the whole life-span, makes it relevant to use also in relation to adult people suffering from COPD.

According to Bøe (2008) the macro system is conceived as environments where the person rarely or never participates, but whom has impact on the person's life and development (Bøe, 2008). In the context of COPD, this level can refer to the political decisions of the Health-department whether or not to prioritize the population, which might lead to financial support making it possible to develop good rehabilitation-offers, which can immerse the development of the illness (Johannesen, 2003, 2007, 2009). The macro-system can also refer to social beliefs, values and ideologies affecting the life situations of the person (Bøe, 2008) in example that the public view upon COPD as a "low-status" disease seems to directly affect the prioritizing and valuing of this population (Gore, Brophy & Greenstone, 2000,Global Initiatives for Chronic Obstructive Pulmonary Disease, 2007, Dager, 2009).

To use the perspective also implies an understanding about how changes in roles related to life events influence and shape the person's personality and identity through ecological transitions (Bronfennbrenner ,1979):

> The developmental importance of ecological transitions derives from the fact that they almost invariably involve a change in *role,* that is, in the expectations for behavior associated with particular positions in society (Bronfennbrenner, 1979, p.6)

It is important to make explicit that Bronfenbrenner (1979) used this term to illustrate role changes related to life-happenings such as entering school and getting married. Even so, it also seems advantageous to use it to illustrate how changes in the environment in relation to how the COPD-client is perceived, seemed to influences his position in this society and his identity and behavior.

4.2.1 Ecological transitions – Adapting to the "sick-role".

Roles have a magiclike power to alter how a person is treated, how she acts, what she does, and thereby even what she thinks and feels. (Bronfenbrenner, 1979,p.6).

Situating Bronfenbrenner`s concept in the context of the chronic illness COPD, makes it natural to link it with Parson's concept of "the sick role" (1951, referred in Lewis & Lubkin, 2002), wherein one looks upon illness both as biological and as a response to social pressure. Alonzo (1980, referred in Lewis & Lubkin, 2002) claims that (…) the sick role is learned and is influenced by evaluation and legitimatization from others" (ibid, 2002, p.27). This aspect is also seen in Bronfenbrenner`s theory (1979), where he suggest that *a role* always implies some expectancy of how to act and of how others are to act towards the person. These expectations are formed in subculture and culture as a whole and "(…) the role which functions as an element of the microsystem, actually has its roots in the higher-order macrosystem and its associated ideology and institutional structures" (Bronfenbrenner, 1979, p.86). This "multi-level view" on role and expectations belonging to the role, might also be used to understand the decision-making process of adapting to the role as "sick".

The starting point of the adaption towards this role seems to be a perceived feeling in the person himself and sometimes his surroundings of a biological decrease in physiological and/or psychological abilities that makes the person unable to participate as before. This decreased ability can make the person and his surroundings feel that he fails to meet the expectation of the society, creating so-called "stigma" (Goffman, 1963, referred in Saylor, Yoder & Mann, 2002)[23]. Stigma presents a huge threat to a person's self-value and identity because it hides all other personal traits, making the stigma the person's new identity both for himself and his surroundings (Saylor, Yoder & Mann, 2002). The role is then shaped by social norms of how to behave when sick, and might for some function as an excuse and explanation for why the person suddenly fails to meet society's expectation. It is important to make explicit that taking on the role as "sick" must not automatically be looked upon as something negative. For some, being diagnosed might feel like a relief, "allowing" them to withdraw from social demands and expectation that they themselves feel that they are no longer able to master. Instead they construct new challenges more fitted to their "new" role and are therefore able to experience mastery and despite the disease. These experiences can also function as a reminder of their still preserved resources while at the same time facilitate new resources through being exposed to new challenges. In this situation, the ecological transition might lead to growth and development for the person (Bøe, 2008).

[23] Stigma is created when there is a gap between the so-called "virtual social identity" – the expected character attributes of yourself and the society, and the "actual social identity" – the attributes that the you yourself actually possess" (Goffman, 1963, referred in Saylor, Yoder & Mann, 2002, p. 55). The reason for referring to Saylor, Yoder & Mann (2002) instead of Gofmann when discussing stigma, is because of their contextualization of the concept in relation to chronic illness.

In contrast, if the person adapts the "sick role" in a way that it becomes his new identity, suppressing all other personal traits and resources, it can cause the person to use the illness as an excuse for fully withdrawing from social life. Ecological transitions might then lead to stagnation and mis-development (Bøe, 2008) by the fact that the sick-role adaption might become a treat to the identity and the self-worth of the person. As Wormnes & Manger (2005) claims, "In the longer run, these roles are disruptive. We get pacified and avoids challenges that strengthens the experience of mastery" (ibid, 2005, p.90, own translation**).** This leads to a lack of mastery-experiences, which can be a huge threat to the self-worth and self-confidence of the person.

In an ecological understanding of illness, the adaption of the "sick-role" also impacts the expectation of the surroundings in the person's abilities to participate and how the others ought to act towards the person (Bronfenbrenner, 1979). In the field of motivation-psychology, the effect of other's expectation upon the person is often referred to as the "Pygmalion-effect" (Wormnes & Manger, 2005, p141)[24]. When relating this effect to George Herbert Mead`s social-constructivist understanding of how the perception of ourselves changes in interaction with other people, (Head, 1934, referred in Wormnes & Manger, 2005) it is easy to see how the person could end up in a viscous circle wherein the person's own expectation to himself, shapes and are shaped in interaction with others. Through repeated experiences of failing, people can get pacified through their focus upon their own insufficiency (Wormnes & Manger, 2005, p.88) leading to so-called "learned helplessness" (Seligman & Maier, 1967, referred in Wormnes & Manger, 2005) and self-fulfilling prophesies of not mastering can begin to dominate the person's thoughts. The persons do then no longer trust in his ability to master any tasks, reducing person's "self-efficacy" (Bandura, 1989;1997). Self-efficacy is a term referring to people's own beliefs about their capabilities to affect their lives and defined as one of the central mechanisms to human agency. (Bandura,1989;1997). When considering that a main source of self-efficacy is personal behaviour history (Bandura, Reese & Adams, 1982, referred in Reeve, 2005, p. 230), a reasonable explanation for the low self-efficacy that people diagnosed with COPD tends to suffer from (Wigal, Creer & Kotses, 1991) might be the constant decrease in physiological abilities that COPD imposes. During the years the memories of the person's resources and personality fade away both to him and to the surroundings. As Wormnes & Manger (2005) claims: "Many people do not remember their own experiences of mastery. The memories that tells them that they have succeeded, is hidden" (ibid, 2005, p.67, own translation)**.** The person begins to accept that he is just a patient that depends on others which might also decrease his feeling of autonomy.

[24] The "Pygmalion-effect" was named after George Bernard Shaws act "Pygmalion" or "My fair lady" as it is normally referred to (Wormnes & Manger, 2005).

When considering that increased autonomy was seen as an important aspect in rehabilitation (Celli and Mac Nee**,** 2004, WHO, 2011) gaining a deeper insight into how a chronic illness influences the person`s autonomy is necessary. Since the concept of autonomy seems closely related to the concept of agency, the latter aspect will also be included in the discussion.

4.3 Autonomy and agency

As stated in chapter 2.3 autonomy is identified as a basic human need (Ryan & Deci, 2000) and defined as "the ability of an individual to respond, react, or develop independently without outside control (Hummel, 2002, p.364). When given the fact that illness in itself has been described as "the ultimate out-of-control experience" (McDaniel, Hepworth and Doherty, 1997, p.6) wherein "some unknown foreign body invades a previously healthy person, often changing them permanently" (p.6). Being diagnosed with a chronic disease like COPD, might impose a huge threat to the person's feeling of autonomy. This can also be related to the act of institutionalization and treatment that a chronic disease-diagnoses often imposes. As McDaniel, Hepworth and Doherty (1997) state: "In a hospital or nursing home, people are too often stripped of their identities and treated as a bundle of organ systems" (p.6). This then might lead to a feeling of powerlessness and helpless in the person, letting himself become totally dependent on others. As Ruud (1998) has portrayed, " (…) one substantial factor related to our medical culture and our health is a feeling of disempowerment, letting our selves be managed and treated (…) (p.61). The feeling of being out of control and totally depending on others, might further lead to an decrease in the person's belief in his own capacities to influence the situation and environment, an experience that has strong links to the term "self-efficacy" (Bandura, 1989;1997) and the concept of agency. Agency seems to be concerned with aspects such as achievement, competency, mastery, and empowerment (Ruud, 1998, p.62), aspects that are closely linked with self-efficacy (Reeve, 2005). When diagnosed with a chronic disease, one might first experience a sudden loss of control over the situation that decreases one's feeling of autonomy. This leads on to powerlessness and a feeling that one does not have the capacities to master the situation, which once again decreases one's agency. The described process seems very much to be the case in the context of COPD wherein several clients suffers from low self-efficacy (Wigal, Creer & Kotses, 1991). When considering that this low self-efficacy are closely linked to quality of life (Kohler, Fish & Greene,2002, Arnold et.al, 2006), dacilitating activities that foster self-management and self-efficacy is essential (Garrod, Marshall & Jones,2008).

4.3.1. A Movement from Failing towards Experiences of Mastery

One way to affect the development discussed above is to facilitate activities that increase the awareness of the person's resources and replace the experiences of failing with experiences of mastering. Given the fact that one source of the person's self-efficacy is personal behavioural history (Bandura, Reese & Adams, 1982, referred in Reeve, 2005), rapid experiences of mastering, can re-formulate the history that the person tell to himself and to others, focusing more on what he is capable of then letting the negative self-profiling prophesies dominate. Through telling these stories, the feeling of mastery can become internalized, making the person believe he is capable of mastering tasks through the use of his resources. In an attempt of linking this back to the discussion of stigma (Goffman, 1963, referred in Saylor, Yoder, & Mann, 2002) and adaption of the "sick-role" (Parson,1951, referred in Lewis & Lubkin, 2002), facilitating activities that demonstrate and clarifies the person's resources and abilities might be one way to decrease the de-evaluation of chronic ill that seems to suppress other traits (Saylor, Yoder & Mann, 2002). Activities that enable opportunities for the client to promote his identity, using his resources and experience mastery thereby seems to be an important strategy to "uncover" the person behind the patient and redefining the domination of pre-set expectations associated with his role.

Since this thesis is written in the context of music therapy, one might ask, "Are there any possibilities in the processes enhanced through a therapeutic use of music that stands in line with the processes of promoting identity, mastery, agency and using ones resources as outlined above?" This is a question whereby its`answer is depending on the context and the people involved. Still, a strong relation between music and identity have been demonstrated both inside the music therapy discipline (e.g Ruud,1997;1998), in sociology (DeNora, 2000) and personal and social psychology (Rentfrow & McDonald,2010). Finding ways to promote one's identity can also be a reminder of resources and competence that can strengthen one's autonomy and agency (Ruud, 1998, Wormnes & Manger, 2005). In the music therapy-tradition, here contextualized to be in Norway, music therapists have been strongly influenced by Ruud` music therapy definition (1990) wherein he suggested that music therapy could give people new possibilities 'to act' (p.24). The aspects in Ruud`s music therapy definition (1990) seems to resonate with WHO`s definition of rehabilitation as a process of giving people tools needed to attain self-determination (WHO, 2011). Music then might be looked upon as a "tool" in music therapy, that when being used in the relationship between the client and the therapist, can help the client increase his agency and mobilize his resources. This could further facilitate an experience of himself as a person who acts and create. Music then becomes a type of health-resource (Ruud, 1998) that can promote experiences of mastery, resources and growth.

> Music empowers us: it gives us a psychological and cultural platform form which to make our own decisions on matters concerning our lives. When we are engaged in music, we feel we are "somebody" (Ruud, 1998, p.62)

This quotation stands in a close relationship to the aspect of a resource-oriented music therapy approach (Rolvsjord, 2004, 2008, 2010) wherein the concept of empowerment is of particular interest.

4.4. Resource-oriented music therapy and the concept of empowerment

As discussed in chapter 2.3.3, the resource-oriented music therapy was originally developed in the mental health-context (Rolvsjord, 2010). Still, given the ecological awareness of the interplay between the client and his environment that the orientation implies, it emerged in the process of this thesis as an important perspective also in the context of holistic COPD-rehabilitation. This is also related to the holistic focus of the orientation, highlighting the balance between working with a person's resources and strengths, but at the same time still not ignoring the person's problems (Rolvsjord, 2008). In addition it also highlights the importance of a mutual and reciprocal collaboration between the client and the therapist (Rolvsjord, 2010), a factor that is highly related to the Ministry of Health and Care services focus (Helse- og Omsorgsdepartementet, 2008) on collaboration with the client in developing the rehabilitation.

The resource-oriented music therapy approach are informed by fields such as positive psychology, the common factors approach, current musicology and empowerment-philosophy (Rolvsjord, 2010). The latter field of empowerment emerged as an important perspective also in relation to this thesis, and will thereby be applied as the main field in relation to how a resource-oriented music therapy approach can be applied in clinical work and research with COPD-clients.

4.4.1 Moving from powerlessness to empowerment

The concept of empowerment has its roots from the civil rights movement in the 1960s and 1970s (Rolvsjord, 2004). Among several traditions, it has been linked with anti-psychiatric and anti-medical movements and it is from the latter movement that the concept will be used in this thesis[25].

In the health-care services of chronic illness, empowerment can be looked upon as somewhat the opposite of *powerlessness*, with the latter being defined as "(…) the perception that one lacks the capacity or authority to act to affect an outcome" (Miller, 2000, p.4). Powerlessness is often experienced by clients with chronic illness, and can be developing from a real loss or a perceived loss of power by the client (Onega & Larsen, 2002). To promote empowerment is therefore identified by nurses as the "goal of their care" (Onega & Larsen, 2002, p.304).

[25] It must be made explicit that because empowerment is always related to a context and are thereby defined by this context (Dalton, Elias & Wandersman, 2001, referred in Rolvsjord, 2004), how the concept is used and defined in this thesis are colored by the thesis` context.

The clinical site wherein most of the rehabilitation for chronic ill happens though, seems to impose some problems in developing strategies for facilitating empowerment due to the fact that they are still under influence of a medical model paradigm (Onega & Larsen, 2002). This paradigm is often associated with an imbalance of power structures, looking upon the professional as an "expert" identifying and choosing methods to treat the patient (Rolvsjord, 2008), making it difficult to facilitate opportunities for the client to gain empowerment. As Onega & Larsen (2002) states: "Within the acute care setting, the health care provider, not the client, is in "control" or has power. A paradigm shift may need to occur for the health care provider to be able to empower the client" (ibid, 2002, p.305). A critique towards Onega & Larsen` statement (2002) though, is their focus upon the health-care provider as the one providing the empowerment *to* the client. This still sounds like an unbalance of power in the relationship with the health-care provider implying an act upon the client. Considering that mutual relationships and self-determination is two of the core aspects of empowerment philosophy (Rolvsjord, 2004) rather than making the health-care provider able to empower the client, opportunities for the client to be able to empower himself should be the focus. The client and the therapist thereby has to develop an mutual alliance where "(…) the therapist and the user collaborates in defining the goals and the methods for further development (…)"(Norcross, 2002, referred in Wormnes & Manger, 2005, p.64.). "This type of relation will in a more advantageous way be able to maintain the clients feeling of having the power, strength and influence over himself, the situation and the wished outcomes" (Wormnes & Manger, 2005, p.64, own translation). To link this up with the aspects of stigma and the "sick-role", mutual relationships seems to enhances the increase in self-worth and is seen as strategy for reducing stigma (Saylor, Yoder & Mann, 2002) by the person increasing the awareness of his agency both to himself and the surroundings. In an ecological approach the increased awareness enhanced trough mutual relations might also be a way to influence and possibly change the perception of the client in his social settings.

4.4.2 Cultural awareness

A mutual relationship wherein the client is seen as an authority in relation to his situation also creates a room wherein the uniqueness of each person's personal, cultural and social background and identity is taken into account when developing the rehabilitation. In the context of a resource-oriented music therapy this can be facilitated through "(…) recognizing the client's goals and to acknowledge the way they are using music and music therapy to improve their quality of life" (Rolvsjord, 2004,p.104). This focus seems also to be present in ecological and transactional perspective to music therapy wherein a more pragmatic view than what has been the focus of the syntax of music has been suggested earlier (Stige, 2002)[26]. Instead of focusing on how the music of the client sounds like, an awareness of how the client *uses* music and "How music is part of the interplay between the individual and the environment" (ibid, 2002, p.141) is seen as the main focus. This focus have clear parallels with sociologist DeNora`s research upon how people use music in their everyday life to regulate social relations, emotions and construct their identity (DeNora, 2000). To be sensitive and acknowledge how the client uses music not only in the therapy, but also in their own life can then be seen as a way to acknowledge the client's own competence (Rolvsjord, 2008). To let the client's own competence be the leading factor for his development in the music therapy, thereby implies that the therapist acknowledge what is important for the client instead of using pre-set methods to try and facilitate development in the client. Considering the fact that some client might have "forgotten" about their own competence or is unaware of how they use it, the first step of the therapist's work might be to make the client aware of his own competence, and then work together with the client to develop and strengthen these (de Shazer, 1991, referred in Wormes & Manger, 2005) In the context of music therapy, this can be done through creating an awareness of how the client uses (or has used) music, create opportunities for the client to re-gain his right to music and use his personal relations with music as a resource for mastery, identity-building and empowerment.

Another link between a resource-oriented music therapy approach and the ecological approach outlined by Stige (2002 is the strong influence of empowerment-philosophy, implying a focus upon the social and political context wherein the client lives within the music therapy session (Rolvsjord, 2010):

> (…) empowerment philosophy somehow bridges the gap, or at least aspires to bridge the gap, between therapy and society, pointing very clearly to the contextual aspects related to health and linking the therapeutic process to the interaction between individual and community" (ibid, 2010, p.81).

[26] With the term "syntax of music", Stige (2002) refers to the focus upon the structure of music as the basis for analysing the interpretations of musical meaning in music therapy. An example of this is Bruscia`s Improvisation Assessment Profiles from 1987 (referred in Stige, 2002).

An ecological view then imposes a perception upon resources as something not existing only within the individual; it is also concerned with the client's access of resources in their social context. To enhance empowerment is thereby both related both to a perceived feeling of being competent related to experiences such as self-esteem and self-efficacy which Rolvsjord (2004) names "an intrapersonal aspects of psychological empowerment" (ibid, 2004,p.101) and to a feeling of being able to have a voice and affect the surroundings. Empowerment thus is "(…) A process which increases individual or political power so that the individual can perform enactment that improves their life-situation." (Gutièrres, 1990, translated and referred by Wormnes & Manger, 2005, p.58).

Related to the discussed factors, a resource-oriented approach seems to be an advantageous approach when working with people suffering from COPD. This is both related to the orientations focus upon the nurturing of strength and resources, the acknowledging of health-potentials of musical engagement and the awareness of the society and culture that the client is part of (Rolvsjord, 2004; 2008; 2010). In addition, the approach underlining of how music can be used to enhance empowerment, agency and mastery all seem to be crucial for the movement from a the sick-role (Parson, 1951, referred in Lewis & Lubkin, 2002) towards a person-role contextualized in the ecological transitions of Bronfenbrenner (1979). To create a bridge from external theory to the empirical material of this thesis, this movement was underlined by the focus group participants as closely related to general perceptions of holistic rehabilitation for people suffering from COPD.

5. PRESENTATION OF THE DATA

As described in the method-chapter all the participants wished to be anonmous, and thereby only codes referring to their professional roles will be used in the presentation of the data. To use this codes seemed advantegous in order to be able to see in the data-material which statement was given by whom in relation to this thesis underlining of collaborative knowledge-building and to show in the analysis how the knowledge of each participant were important in the development of a substantive theoretical perspective. To make it easier to understand what the codes referres to, I found it important to make an overview before presenting the data-material.

C.R.= COPD-Representative

M.T.= Music Therapist

P.T.= Physio Therapist

A.N.=Auxilary Nurse

D.= Doctor

R.= Reseracher

5.1.The emerging of themes and categories

When analyzing the focus-group interviews between each meeting, a pattern of two main topics emerged from the empirical material. One was related to aspects of a holistic rehabilitation and how music therapy could take part in such rehabilitation, while the other one seemed to be more related to music therapy's contribution in COPD-rehabilitation.

In discussions about how the nature of an interdisciplinary collaboration in general should be carried out to facilitate holistic rehabilitation, a key theme seemed to be reciprocal and mutual dialogue and knowledge exchange between the professions and the client himself. This process was also looked upon as crucial for the integration and contribution of music therapy in a holistic COPD- rehabilitation. Related to music therapy's contribution, themes emerging focused both upon functionally use of music to enhance better breathing and as derivation in physical training and towards the more psychological and psychosocial issues such as resources, mastery, acknowledgment, and positive experiences.

Given the fact that the functionally contribution of music therapy has been one of the main topic for research upon COPD and music therapy (Engen, 2005, Bonhila & Onofre et.al, 2009), the focus of this thesis will mainly be upon the psychological and psychosocial issues, which combined with the functional, might contribute to gain a more holistic picture of music therapy's possible contribution. Still, as outlined both by the doctor, the physiotherapist and the auxiliary nurse, music therapy's contribution for improving the breathing-pattern was seen as important to improve the overall life-situation of the client, illustrating the relationship between mastering of symptoms and mastering of life.

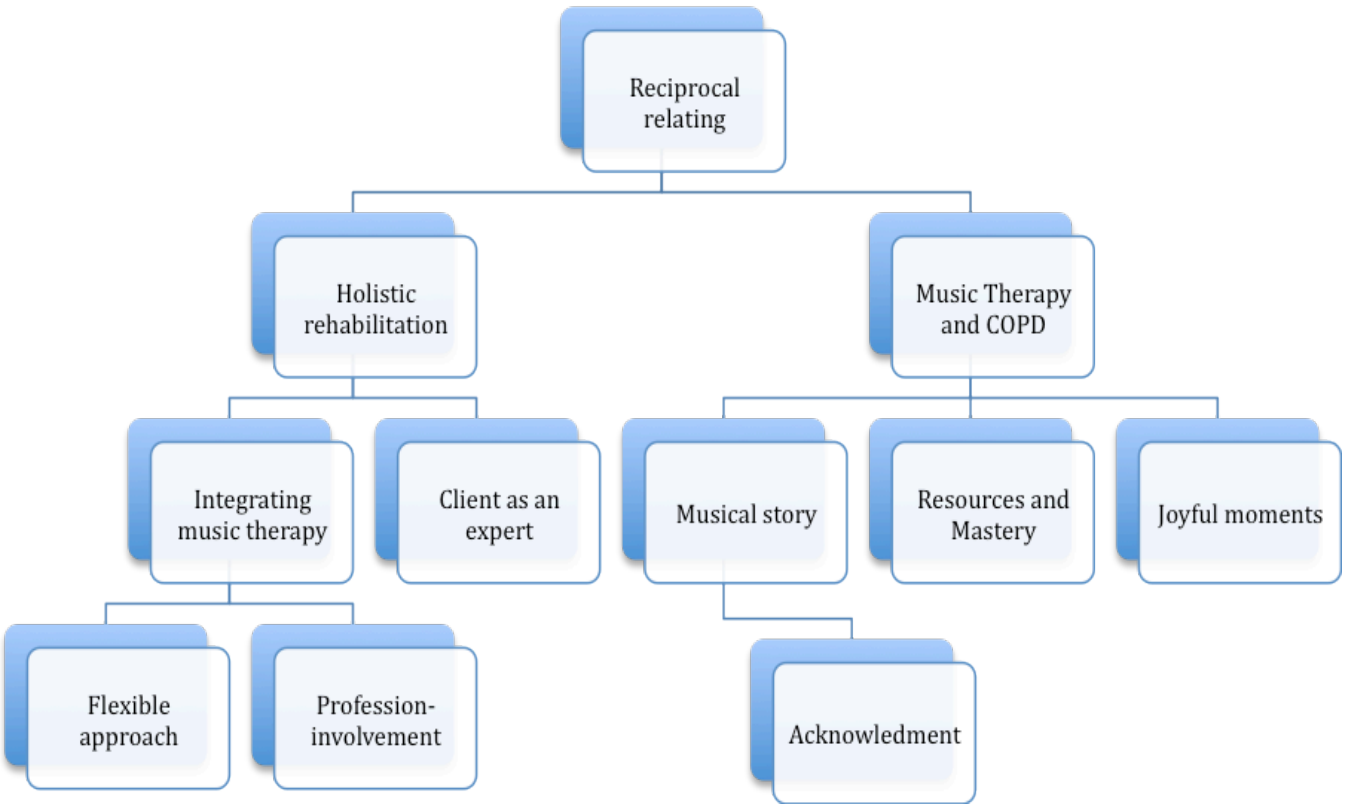
It is therefore important to underline that the use of music to address functional or/ and psychological/psychosocial needs are closely related to one another. As the physiotherapist outlined:

P.T: It (the music) gives you so much in so many way, both an improved physical function, but also a good feeling inside you (…)

When working with people suffering from COPD, it was seen to be advantageous by the focus group that the music therapist accounts for and approaches both the functional and the psychological/psychosocial aspects. This aspect will be further discussed related to the category of "Flexible approach".

As discussed, a key theme in the focus group discussion was reciprocal relating both in the interdisciplinary collaboration between the client and the staff and in order for music therapy to be integrated it's level of contribution. Figure 1 (see below) provides an overview between the main categories and the subcategories. A broader discussion about the core category of *reciprocal relating* will be given at the end of this chapter.

Figure 1



5.2 Holistic rehabilitation

As discussed in chapter 2.3.1 the word "holistic" has received a growing attention both in the health-society (Helse- og omsorgsdepartementet, 2008, Hanser, 2010,) and in the general public society (Fugeli & Ingstad, 2001). In the empirical material the focus group participants seemed to relate the concept of holistic rehabilitation both to the concept of interdisciplinary collaboration, to a general view of seeing the human being as a whole and a more specific view related to how one perceives the patients.

In relation to interdisciplinary collaboration, the focus group participants outlined the necessity of reciprocal knowledge exchange between the professions and the client in order to develop a holistic rehabilitation. As the physiotherapist stated the last interview:

P.T: (...) that was almost the first sentence we said, that thing about us being a part, that nobody can say that they know everything about the patient, no disciplines are able to do that. Everybody knows parts of something.

The need for collaboration was outlined as mainly being due to the complex and changing nature of COPD. For someone to know everything then was looked upon as impossible. By gathering the "knowings" of each profession and the client, the focus group stated that they might be able to create a whole, but as they outlined, the processes of influencing and developing each other's knowledge change this "whole". This might be linked with the core of the general system-theory Von Bertalanffy (1950), wherein he stated that "the whole is more that the sum of its parts" (p.142) and that the systems[27] always open to external influences, shapes and re-shapes itself through gaining new knowledge (Von Bertalanffy, 1950,Wormnes & Manger, 2005, p.13). The whole, in this context referring to a holistic COPD-rehabilitation, does then not only consists of each member's knowledge summed up, rather it is a result of the shaping and re-shaping of knowledge facilitated through the process of reciprocal collaboration.

The focus group also used the term holistic as a way to describe a general view upon the human being:

D: (...) so the history in a way, the whole human being, both the physical and the psychological, the spiritual, the essential or yes…the social, so, all of it

This seems to resonate with the Oxford Dictionary (2011) descriptions of the medical use of the word holistic (Oxford Dictionary, 2011) (see chapter 4.1.). As discussed in chapter 2.1, to take into account especially the social factors in the treatment of a person might point towards the ecological perception of health and illness (Bruscia, 1998).

[27] In the general system theory, "the system" is used describe biological, machinery and social systems (Von Bertalanffy, 1950)

This links is also seen in relation the focus group medical related perception of the word "holistic" wherein they underline the importance of seeing the patients as more than his diagnose. In an ecological understanding this might be related to ecological transitions (see chapter 4.2.1). As the focus group outlined, a holistic focus could be a way to change the role from patient to person

A.N: See you as a human being and the completeness, right. Not only your diagnosis, that you have COPD right and…but to see you as a person, right.

"Seeing the patient as not just his diagnosis, but as a person" was a phrase that kept coming back in discussions of the focus group, both in the overall situation, but also more specifically related to music therapy. In this view, the focus group participants underlined the importance of taking into account the person's life-history, which seems imply the importance of taking into account the cultural and social aspect when treating the patient. As the doctor outlined to the COPD-representative:

D: You have lived a long life and that is what shapes you (….) because even though you have an disease, well that is that, but you are not the disease, you are you.
Several: Mhm, yes

To take into account the clients` life history in the rehabilitation was seen as especially important related to clients suffering from a chronic illness such as COPD. As the doctor said:

D: Off course it does something with a person to have this type of illness hanging over you.

The focus group's focus underlining of a holistic rehabilitation as one that sees the whole person and takes into account his life history might point towards a link between a holistic rehabilitation and an ecological understanding of COPD. This link is also seen in the focus group outlining COPD as disease being under-prioritized because of the society's view upon the disease as self-inflicted, a factor which can be related to the exo-system of Bronfenbrenner`s theory (1979) wherein actions in social layers where the person does not participate still can influence the person's life (ibid,1979).

5.2.1 Client as an expert

M.T: And as you say COPD-representative together with the doctor, that the one that has the shoe on, knows where it hurts, that you are the one that know most about how you feel with your illness, you are the expert on it
C.R: (Cries a bit)

In this statement, the music therapist touches upon some of the core of what type of role the focus group participant suggested as advantageous for the client to withhold, namely as an "expert". The reason for this, as outlined several times, was that nobody, except from the patient knew exactly how it felt like to carry the illness. To put the client in the centre of the rehabilitation was thereby seen as the most advantageous way to be able to develop a holistic rehabilitation that addressed the client's complex needs. The participants also outlined that the main strategy for giving the client this role as an expert was to learn and be influenced by him. They also talked about the importance of the client learning techniques from them to in example enhance better breathing, so that he could use this by himself in his everyday life, pointing towards that mutual and reciprocal process was also present in the collaboration with the client. The COPD-representative also seemed to agree on the importance of being a part of this type of collaboration.

R: But do you see it as important to be allowed to participate in the dialogue?
K.R: Yes! I think so
(…)
R: What do you think is important for me to know about COPD then?
C.R: You get familiar with it now, when you talk to me and ask, then you get the answer from me about how it is.

Giving the client the opportunity to tell about how it is and use this as a starting point for developing the rehabilitation seems to a core aspects the resource-oriented music therapy approach's perception of mutual relationship (Rolvsjord, 2004). In addition, as stated by the physiotherapist the client's state and needs might change during time, and one should thereby always be open to new information from the client, that could influence the rehabilitation. To give the client opportunity to tell how he feels also during the rehabilitation might be a way to maintain this mutual collaboration throughout the whole rehabilitation-process.

P.T.: Yes, both the knowledge as a basis, but also along the way, the information along the way (…) That you tell how you are feeling, that you have reached your limit or that this is enough. (…) Right, that you are able to tell along the way are also important, that dialogue and that type of knowledge.

An example of how important this information might be was stated by the COPD-representative.

R: Related to last interview, you said that playing the harmonica…that you felt it was okay…
C.P: Yes, but I think that it is to small, I want a bigger harmonica because it is so small that only chromatic tones comes out of it. And then it just stops for me (…) and I get nothing.

This is an example of how important it is to give the client the opportunity to say what he needs and want in order for him to fully benefit from the rehabilitation. This means letting the client take "the driver`s seat" (Rolvsjord, 2004) and give him the opportunity to at any time give information about how he feels and how he might experience different aspect of the rehabilitation. These aspects might be further linked to the concept of agency and autonomy (see chapter 4.3) related to the fact that it might enable a experience in the client that he is able to take control and take decision concerning, in this context, the outline of the rehabilitation.

M.T: (…) and that it is your self as a person who contributes, you are not totally depending on others to help you all the time.

The quotation of the music therapist was said in relation to how facilitating opportunities wherein the client can experience himself as the one contributing in the rehabilitation, could promote mastery and motivation. As Wormnes & Manger (2005) claims: "Improvement in achieve something increases the motivations and affects the individual self-perception (ibid, 2005, p.29). The music therapist statement, combined with literature might then point towards a type of inter-relating process between the aspects of agency, mastery and motivation, wherein agency promotes mastery which then further can promote motivation and the other way around. This cyclic process was discussed at several occasions by the focus group.

In addition to this, the focus group participants underlined the importance of letting the client decide whether or not he wanted the role as an authority and an expert:

M.T: But I think it is also important that, off course should the one who owns the illness be informed and be included in every decision, but at the same time, one should not have to be responsibly for that we know about each other. (…) You that sit in the middle should not feel like being the information link in the whole process.

This aspect can be related back an important aspect of agency and autonomy namely that forcing the client to take on the role, as an agent in his life is actually a way of decreasing his autonomy. This can be related Lewis and Lubkin (2002) stating that not all patients are comfortable in taking on a participative role (p.44). This statement is closely related to a study of Stiggelbout & Kiebert (1997) that through questionnaires studied the correlation between personal characteristics and preferred role.

This was done through comparing a sample of 55 patients with cancer, 53 persons accompanying them with a sample of 53 patients visiting a surgical outpatient clinic for a nonmalignant condition and 36 persons accompanying them (Stiggelbout & Kiebert, 1997, p.383). The conclusion pointed towards the importance of all clinicians to assess every patient individual to determine their preferred role. Stiggelbout & Kiebert (1997) also suggested that the fact that the patients preferred a more passive role than their companion the `sick role´ played a large impact upon the role-decision (ibid, 1997, p. 383). Thus it seems most advantageous to decide the preferred role in collaboration with the client and always be open to changes related to their evolving illness and the impact of the illness upon their role and identity.

5.2.2 The integration of music therapy

The focus group members all seemed to agree that establishing music therapy, as part of a holistic COPD- rehabilitation seemed advantageous. This was mainly related to the processes that music therapy seemed to facilitate that was though of as standing in close relationship with those aspect of an holistic rehabilitation that the focus group participants outlined.

The focus group participants outlined two main strategies for how to integrate music therapy in the holistic rehabilitation. One was the ability of using flexible approaches and finding a balance between addressing the symptoms and promoting the client's resources. The other was to involve the professions in the music therapy-sessions, so that they were able to see how music therapy could contribute with COPD-clients and how the music therapist's approaches could influence their work. The latter was also seen as advantageous by the COPD-representative because it increased the possibilities for him to use the some of the activities in music therapy other times during the day. To involve the profession was also though of as a way of increasing the flexibility of both the music therapist and the professions, because of the reciprocal knowledge-exchange that seem to be facilitated when working together. A quotation from the auxiliary nurse can be used to illustrate this reciprocal process of influencing each other's knowledge and work:

A.N.: Yes, because we have to, it kind of goes both ways right, because you have to know how we work right, about how the everyday life of the COPD-patient is from he gets up until he goes to bed again (…) And for us to be able to put music into his everyday life, we kind of have to see a little bit about how you work.

To establish music therapy then, both implied some development and even some possible change both in the knowledge of the music therapist and the other professions.

5.2.3 Flexible approach: a balance between symptoms and resources

One of the main aspects of what the focus group considered as important in order for the music therapist to work with people with COPD, was basic medical knowledge.

D: I am thinking that a little bit of medical-knowledge is not something to despise
R: Yes, do you want to say something about why this might be a good thing to learn?
D: No, I am thinking that one does not get so surprised if there is a sudden decrease and then an improvement again and that one understands more of the process of it. And that there are many stages of COPD
R: So that one gets insight into these processes in a way?
D: Yes, I think that might be a bit okay
P.T: Yes, I also think that
R:Yes.Is there something else that you think should be added or?
P.T: No, just some basic knowledge about how the lung functions and the production of phlegm and so on.

To withhold some medical knowledge was also seen advantageous by the music therapist:

M.T: (…) to be able to have some medical knowledge, to have a little amount of knowledge and to know where one can allocate more knowledge, that is just as important. It has something to do with credibility when you present a new discipline (…)

The music therapist also saw the process of increasing medical knowledge as something depending on the opportunity to be in a team, in order to know where to "allocate more knowledge" as she stated. The main reason for increasing the medical knowledge seemed to be based on the fact that COPD is a complex, medical disease and that the music therapist needed a broad knowledge-base to know both how to address and increase the mastery of symptoms while at the same time enhancing resources for the mastery of life. A discussion between the doctor, the COPD-representative, the auxiliary nurse and the physiotherapist can be used to illustrate the need for also addressing the symptoms in music therapy in order to increase the general quality of life:

D: You know, if you engage in music and singing then you fill up the lungs really well, right, and you broaden the whole barrel that the lungs are, and that is really good (…)
P.T: And the endurance is extended?
D: Yes
A.N: You are using your lungs more actively
(…)
D: And it is so clear, that if one is able to breath better it has an impact on the disease (…) it counteracts the disease, one can say. (…)
(…)
D: And if you are able to increase, you know the breath and the muscles and…around the lungs and those things, it gets so much better
C.R: Yes
D: It does, do you notice?
C.R: Yes
D: Yes, I also believe so

(….)
D: (…) the breath is essential (…) so the breath, to breath freely, really important, both to be able to feel well and be able to function
F.T: Yes, that is the core here.

To withhold some medical knowledge that one could use in the music therapy session to enhance better breathing then, seems to be an important factor outlined by the focus group participants. Still, they underlined the importance of keeping a balance between being aware of the symptoms, while not being "captured by it":

D:. (…) on the other side it is important to not get to focused on it, but to enhance the healthy, good, normal function
M.T: Yes, because there is a distance between being capture by the diagnose-criteria (…) but at the same time…to check if there is something that is medical unjustifiable

The discussion of the doctor and the music therapist can be used as a direction towards the core of what seemed to be music therapy's main contribution in a holistic COPD-rehabilitation; namely the therapy's opportunities to address both the symptoms and work with the resources at the same time. Two outlines from the COPD-representative in the first and second interview can be used to illustrate this combination. In these quotations, he talked about his own experiences of playing the harmonica, an instrument that he used to play on before. To have the opportunity to play on it again then, seemed to function both as a reminder of a personal resource and as a tool for enhancing the breath.

R: You have also tried, we also tried to play a little bit on the harmonica yesterday, that was also something that you..
C.R: Yes…but it is…such a long time ago, it kind of slips away from you a bit…it takes some time…and then, you are into it again.
(…)
R: Can you tell a bit about how you experienced it
C.R: Well…I felt that it was good…Yes, I did.
(…)
R: But, what do you think that it can be used in relation to…yes, the breath and everything then?
C.R: Yes, you know, to play on such a small harmonica it goes in and out. If you have a bigger harmonica then you don't have to do that.
R: So, it is almost more exhausting to play on a little one then?
C.R: Yes, I feel so
(…)
R: (…)but could that be positive in a way in relation to the breath?
C.R: Yes, I think so

The COPD-representative's statement seems to illustrate a type of two-folded experience of both regain a musical interest and use this interest both as a way of feeling good and as a way to improve his breath.

Considering the doctor's, the auxiliary nurse's and the physiotherapist's outline of how the breathing affects the general state of how one feels, it is reasonable to think that the experiences of the COPD-representative are tightly interwoven with each other. In addition, this balance between symptoms and resources seems somewhat to be linked with aspects of a holistic rehabilitation.

M.T.: Well, it is kind of two-folded this. One aspect is to accommodate a musical interest and the other aspect is to use this musical interest to benefit in the whole situation of the patient.

5.2.4. Profession-involvement: Developing each other's knowledge base

R: What should one underline then, yes in a interdisciplinary collaboration, what should the music therapist do to work interdisciplinary or to be integrated in…
A.N: I am thinking that it is really important for us to also be able to use it in our everyday life and work with the tings that the music therapist does, that we are present and actually see how you work

In the quotation of the auxiliary nurse, she touches upon a main theme discussed in the focus group related to how music therapy can be integrated in the COPD-rehabilitation, namely for the other professions to be present in the music therapy sessions. This was supported by several of the other participants. The reason for this seems to be that music therapy was perceived by the focus group as a quite new and un-established discipline, both in the general medical-society and especially in relation to the COPD-population. This aspect lead to a lack of music therapy-experiences making the staff un-certain of what was addressed in music therapy, how it could contribute and how it could be integrated into the other professions working approaches. This can be illustrated by a quotation by the physiotherapist:

P.T.: So I have said to you (music therapist) that I really want to be a fly on the wall, because it is something about it, I think that if people doesn't know so much about what you do, I almost have to guess what.

For the other professions to be able to participate and see example of how music therapy could be used then, made it easier to know how to be influenced by it. It also made it easier for the other profession to understand how music therapy could contribute when working with COPD-client.

P.T: (…) you can tell and you all can see how good it works and thereby it will be able to be spread itself a bit more (…) if one doesn't know that this might be something, that one need a bit of an awakening and seeing concrete examples of it

This then points towards another aspect of the integrating process, namely that the understanding created through participation of how music therapy could contribute, might make it easier for music therapy to "spread itself more", increasing the changes of becoming integrated in the COPD-rehabilitation.

It thereby seems to be some kind of reciprocal and inter-relating process between increased understandings leading to increased acceptance that further could lead to increased possibilities of integration in the COPD-rehabilitation. This aspect is also seen in literature, wherein Twyford & Watson (2008a) outlines that to experience music therapy first-hand seems to lead towards a greater understanding of music therapy.

5.3. Summary

The focus group seemed to underline the importance of a holistic rehabilitation for people with COPD, both related to increasing the focus upon the client as a person, not just his diagnosis and in relation to the complex nature of COPD. Due to the latter, mutual and reciprocal relationships between the professions and the client was seen as a necessity for a holistic rehabilitation to be established.

Considering that a holistic rehabilitation was seen as concerning the whole human being, to gain a broad knowledge base was seen as advantageous for the music therapist to be able to work flexible with the symptoms and the resources together with the COPD-client. For music therapy to be integrated in a holistic COPD- rehabilitation then, seemed to depend on a reciprocal knowledge exchange between the other professions and the client. In this reciprocal collaboration, the music therapist could increase her medical knowledge needed for a flexible approach, while at the same time, the other profession could increase their knowledge and understanding of how music therapy could contribute in a holistic COPD-rehabilitation.

5.4 Music Therapy and COPD

D.: (...) music is a fantastic language and it is not a disease-language

The outline from the doctor might illustrate some of the core in how the focus group participants stated that music therapy could contribute. Music in itself was seen as something associated with personal memories, experiences and relations to other people. When used therapeutically and systematically through music therapy, all these associations contained in music, could promote positive emotions, personal resources, mastery, motivation and uncovering the person's identity through their music story. When considering that the focus group looked upon chronic illness as a threat to the person's identity, the processes enhanced through music therapy fostering awareness and acknowledgment of the person's identity, was looked upon as highly important.

5.4.1 The Musical Story: Uncovering the person behind the patient through exploring client's musical relations

M.T: I am thinking that what music therapist can contribute with in particular is to explore and make an overview of the person in the music

In the statement of the music therapist, she describes how the music therapist can explore and make an overview of the person's life in music. In the un-translated version she calls this "en kartlegging av mennesket i musikk" meaning that one can almost create a map of the person's life history through music. This has quite clear parallels to Ruud`s perception of music as a (…) flexible map of our own life-world (…) (ibid,1997, p.58, own translation). The best way to do this, she claimed was through registration of the client's musical preferences:

M.T: I see it as an important part of my work to register what I call preferences (...) and I think that is important information about the patient.

Using the client's musical preferences to gain information seems advantageous considering research upon musical preferences and personality showing a quite clear relationship between the personal traits of a person and what type of music a person prefer (Rentfrow & McDonald,2010) Still, as Rentfrow and McDonald (2010) states, music preferences might changes during your life and there is a need for research upon these changes (ibid, 2010). This change in musical preferences can also be seen in the music therapist illustration about the "mapping of the person in music". She seems here to be pointing towards exploring the different "land-marks" or in other words life-periods of the person's musical history that as the focus group claimed was highly associated with memories of life-events and relationship with other people. As Ruud (1997) further states about the musical map: "(…) the map can change when we re-create the history about our self through music" (ibid, 1997, p.58, own translation).

The perception of how the identity of a person changes when living with a chronic disease, as both stated by the focus group and seen in literature (Lubkin & Larsen, 2002, Lewis & Lubkin, 2002, Saylor, Yoder & Mann, 2002), might point towards a reflexive view upon how a person creates his identity. Instead of looking at the self as a firm core, a person throughout his life shapes and re-shapes his personality and identity. According to Ruud (1997), through telling the stories of our self we then are "who we create ourselves to be" (Ruud, 1997, p.52) and we use different means to present ourselves, as our self (ibid, 1997). The identity then becomes something that we construct, and through this construction we make a statement about who or what we want to be and where we want to belong (Ruud, 1997). Authors from several disciplines has outlined that music can function as a mean for constructing and presenting ourselves, both our personal and social stand (Ruud, 1997;1998, DeNora, 2000, Rentfrow & McDonald, 2010). As Rentfrow & McDonald (2010) state: "(…) individuals use music as a badge to communicate information about themselves (…) (ibid, 2010, p.685). For the COPD-representative in example, he used his participation in a choir to tell something about himself.

C.R.: I sang in a choir for many years
(…)
M.T.: Which choir did you sing in, then?
C.R.: Well…I sang in x (the name of the choir) down at x (the choir's site)
M.T: Exactly…yes…men's choir or mixed choir?
C.R.: No, it was a men's choir
D.: Wow, that's great

Singing these songs in the music therapy then, was something he outlined as a positive experience both emotionally, but also physically, because he remembered how the conductor had instructed him to breathe between the phrases. He was able to use his own knowledge related to his musical background to do something to help address his breathing, while and having the opportunity to tell something about his own background. It must be made explicit that according to the focus group participants prior active music engagement was not required for using music as a way of telling ones story.

M.T.: And I am thinking that one doesn't have to have been actively engaged in music or played an instrument or sung in a choir, but..ehm..most people have something that is connected to music, right, like being fond of dancing in example..
A.N. & P.T.: Mhm
M.T.: Or has used music when cleaning the house, listened to the radio and those associations can be used further

In the statement above, the music therapist highlights how memories of interest and daily activities is somewhat contained in music.

The fact that people uses music in their daily activities is also supported by DeNora's research (2000), wherein she states that music afford certain qualities and opportunities for how it might be used, wherein it is the person himself who decides or appropriate how to use it.[28]. How the person has used the music in their life then, seems in the empirical material to contain important information of memories of environments and actions wherein the music was used. This might be linked with one of Ruud's four "categories" of how music constitutes identity; namely "the space of time and place" (Ruud, 1997;1998). Music, according to Ruud (1997) are always related to a certain time and space and because of that, music becomes markers of important "time-place" experiences for the individual's own life history (ibid, 1997). As further stated by several of the focus group participants, using preference-based music was seen as a way to provoke these memories and create associations to particular life-events. It is also reasonable to think that different life-events contained different emotions and feelings and that through the use of music, these feelings could be awakened and explored (DeNora, 2000). As the auxiliary nurse stated:

A.N.: Music can create moods, what type of emotion music can awaken in us are both positive and negative things, really.

The proposal of the auxiliary nurse that music might awaken both positive and negative feelings, underlines the necessity of the music therapist to be sensitive towards the client's associations with music pointing towards the aspect of preference-based music as discussed above.

In sum, the musical story of a person according to the focus group participants was looked upon almost like a "personality-information-channel" wherein being used in music therapy could uncover important aspects of the client's personality, identity and background. The focus group then saw this as the starting point for how music therapy could foster of resources, mastery, joyful moments and acknowledgment. The latter can be illustrated through a sequence wherein the COPD-representative reveals that he plays the accordion:

C.R: I play the accordion
D: No way?! You do? Regular or "torader" (Norwegian form of accordion)
C.R: Ehh..it is…it is two…ehm…no, it is regular
D.: Amazing.
(…)
D: Have you played at dancing-arrangements or songs or choir or?
C.R.: No, no…I have only played..ehm….what was I suppose to say…wildly
D.: Played wildly? Well, then you must have a good ear for music..amazing!

[28] The term "affordance" are originally retrieved from the perception-psychologist Gibson (1979) whom described how each environments affords a certain amount of actions and perceptions (Gibson, 1979, Ruud, 2008).

5.4.2. Acknowledgment

D.: (...) we focus upon the person, we don't see that you have a lot of COPD, but rather that you have played the accordion and that you can participate and play again right?

Through the latter statement in the previous chapter and the beginning statement of this, a strong link between how the COPD-representative's revealing about his accordion playing seemed to promote a type of acknowledgment and a focus-shift from a disease- towards a personality-focus. The doctor's statement above was also related how one could promote a resource-oriented focus which then might make it possible to draw some reciprocally links between the person's musical story, his resources and acknowledgment by others.

The word *acknowledgment* seems to refer both to the acceptance and the recognition of something or the action of showing that one has noticed someone or something (Oxford Dictionary, 2011). To *be acknowledged* then refers to being recognised of being good or important (ibid, 2011). When considering that a chronic illness such as COPD might reduce the person's abilities because of impact of the illness itself and the expectations of other's and themselves upon what the person are capable of doing, being recognised and accepted as good or important might be a lacking experience for someone with a chronic disease. To find ways to promote those traits that reminds the person and his surroundings about his still remaining personal abilities and resources seems to be highly important, especially in relation to stigma (Saylor, Yoder & Mann, 2002).

According to the focus group, music therapy was seen as promoting acknowledgment on several layers, both through the client's musical engagement and through the relationships that could be created when playing music together, both with the music therapist and in a possible music- group. Related to the former, the auxiliary nurse stated:

A.N.: (...) All human beings have a need to be seen and I really think you are seen in such a setting. That you have social contact with another human being something that we in the nursing-staff constantly have a bad conscience about because there are simply not time to talk with them, right. So just to have another person sitting there, talking to you and playing music together with you and those kinds of things, it does something with you.

It also seems like the acknowledging-experiences in music therapy could create ripple effects to other setting wherein the client interacted. The auxiliary nurse outlined an example of this:

A.N.: And it is very nice to see that you have started to use it again, because it has been standing on the floor on your room and just been standing there
C.R.: Yes

In this sequence, the auxiliary nurse talks about the fact that the COPD-representative has started to play on his accordion again.

At one occasion, he actually played for the staff when they visited him at his room, something he himself stated in the focus group as a nice experience (although he felt like practicing a bit more before doing it again).

One might say that the focus group outlines somewhat of an ecological understanding of acknowledgment through describing different settings wherein the acknowledgment facilitated through music therapy, could have an impact. To relate it to Bronfennbrenner´s ecological model (1979) the acknowledgment was seen happening both at the micro-level, in face-to face interaction that the client directly engage in (e.g the client-therapist relationship), at the meso-level between the settings wherein the client participated (e.g. the music therapist sessions, his music-making to the staff) and at the exo-level, wherein the client's did not directly participated, but where events occurring affected, or where affected by what happened in the setting containing the person (Bronfenbrenner, 1979) (e.g. the music therapist and the professions mutual information exchange of the client's musical interest and background affecting the staff's perceiving of the client) [29]. These interactions then further seemed to facilitate a role-change, or in somewhat ecological transitions (see chapter 4.3) in how the client was perceived: from a patient with COPD to a person, as in this context outlined by the doctor "playing the accordion".

5.4.3 Resources and Mastery

M.T.: Because a little bit of resource-orientation doesn't ever hurt and most people are thinking resources, but and within something so particular as the story of music there is a lot of resources. (...) and then you go through the story of music which is a story about resources and view it in parallel with the illness-story.

In this statement, the music therapist outlines several factors. First of all she proposes a general resource-focus among people, secondly she claims that the story of music is a factor that in particular contains a lot of resources, while third outlining a flexibility between the story of resources and the story of illness. The first factor about people in general having a resource-oriented focus is also an aspect seen within the music therapy-discipline itself (Rolvsjord, 2008). As Rolvsjord (2004) states, the focus upon and nurturing of the client's strengths and resources is not a new thing in music therapy. An example of this used by Rolvsjord (2004) is the Nordoff and Robbins tradition related to the nurturing of the child's musical and communicative resources, also described as the "music child" (Aigen, 1998 & Nordoff & Robbins, 1977, both referred in Rolvsjord, 2004).

[29] It might also be reasonable to think that the acknowledgment might also be related to the client's relatives, but this was not a topic discussed in this focus group.

According to Rolvsjord (2004) several other music therapist also outlines directions which can be seen as representative in resource oriented framework, among them Ruud`s (1998) and Bruscia`s (1998) outline of music therapy as a promoter of health and quality of life (Rolvsjord, 2004). But as Rolvsjord (2004) states, several of these models focuses upon the use of resource to decrease the problems and symptoms. In a resource-oriented music therapy then, this factor is taken into account, but in addition, to use one's resources does not automatically imply to neglect one's problems (Rolvsjord, 2004), an aspect that might be linked with the need for flexible approach as discussed in chapter 5.2.3. As the music therapist in the focus group states, one could rather see the resources in parallel with the illness, which according to Rolvsjord (2004) implies using one's resources to constructively being able to work with one's problems. In the context of COPD-clients, this might be to use music therapy to both develop ways to master the symptoms, i.e. the breath, which as discussed under the category "Flexibility" was seen as by the doctor and the physiotherapist as important for the general mastery and quality of life. As the music therapist outlined:

M.T.: But I have seen several COPD-patients that I have worked with, they have said that they have managed to move the breath from here (points at the chest) (…) and used it to be able to breath with the whole breathing-organ

As outlined in chapter 5.4.1 the musical story of a person, was seen as the main starting point for how the music therapy process could foster resource and mastery, and as the music therapist stated: "*within something so particular as the story of music there is a lot of resources"*. This might be linked to the resource-orientation's perceiving of music as a health-resource (Ruud, 1998, Rolvsjord, 2008; 2010) that can promote vitality, a feeling of belongingness and experiences of mastery and agency (Ruud, 1998). To facilitate opportunities for the client to gain access to, use and explore this story is thereby also an important aspect of resource-oriented music therapy. Related to the context of COPD, the COPD-representative outlined that being diagnosed with such a disease was one of the factors for why he had stopped playing his accordion. In the focus group then, the COPD-representative talked a lot about how he through music therapy had started playing the accordion, the harmonica and singing his male choir songs again.

D.: Do you manage to play now?
C.R: Yes
D: You do so?
C.R..: So, yeah…no..it takes…it takes some time and then you get into it, get into it again
(…)
C.R:Because when you have been away from it, then you loose…you do, and then you have to…it comes back again now. And when we first started I was overwhelmed about how the ability to play had decreased. So then I had to start all over again, but then it doesn´t take that long before you are back on it again

One of the aspects describe by the COPD-representative is his overwhelmed experience of how he feel his ability to play had decreased. Considering that he had been playing actively before he got ill, to start using the instrument again could quickly become a demonstration of his loss of abilities rather than an experience of still preserved resources. As the music therapist stated it was thereby important to get an insight into how the resources and the interest had been helpful for the patient before and use this further as a profit for the person. The focus group talked in example a lot about the use of music as a mood-creator and it is not impossible to think that clients, in this context the COPD-representative, had used his accordion as a way to of feeling better. It then becomes important to focus upon how the client's own use of music can be used in ways that is helpful for them in relation to their situation now. To identify those aspects that the client himself felt was important to promote also seemed to be one of the main aspect of the focus group's discussion about resources then.

M.T.: How have the resources, interests been helpful for the patients before. I know that you, physic therapist have talked about the opportunity to use knowledge and things that one care about doing and use it as a profit for the person

To be able to identify these aspect, a mutual collaboration with the client throughout the whole rehabilitation-process, was seen as necessary, linking these factors back to the discussion of "Client as an expert" (see chapter 5.2.1).

It must be made explicit that the facilitation of those resource-oriented processes that musical engagement according to the focus group, could promote, was not only related to the client`s former musical background. To use music therapy as a way of also gaining a musical interest was seen as advantageous.

R.: But I was thinking that you (COPD-representative) are in some way privileged, you have sung in a choir and you both have a background of playing accordion- and harmonica, but not all COPD-patients has that background. But do you think music therapy still could contribute?
C.R.: Yes, if they haven't been into it before than they get into it now, then I would think that (...) this is a golden opportunity (...)
(...)
R.: Yes, so that they could gain an interest then?
C.R.: Yes, I would think so
R.: Yes, mhm…what do you others think about that?
A.N.: Off course they could. Gain an interest if they haven't, if they themselves haven't been engaged that much in music before.

How then could the experiences of musical engagement or of gaining a musical interest contribute in relation to working with client suffering from COPD? One of the central core, seemed to be how musical engagement through music therapy could promote mastery.

R.: What do you think are the consequences then, if music therapy is integrated in the COPD-rehabilitation? What do you think music therapy in way could…
D.: Well, I think that several patients could improve their experience of mastery or is that right?
C.R.: Yes

According to the focus group participants, the experiences of mastery were both related to motivation, positive experiences, increased self-confidence and acknowledgement from others. This is also outlined by Wormnes & Manger (2005) stating that experiences of mastery are closely related to the development of self-confidence. As discussed in chapter 4.3, the experiences of mastery are also conceived as a source for strengthening the self-efficacy and agency of a person (Ruud, 1998, Reeve, 2005), which is closely related to quality of life for people suffering from COPD (Kohler, Fish & Greene, 2002, Arnold et.al, 2006). When considering that people with COPD often suffer from low self-efficacy (Wigal, Creer & Kotses, 1991) facilitating experiences of mastery are essential for fostering of self-management and self-efficacy (Garrod, Marshall & Jones,2008).

D.: Yes, and I think, if you master something and manage something and feels that this is something that I know how to do, it does something to one's identity and the feeling of dignity as a person, right. I can! (…)
D.:(…), if there is something that I haven't been able to manage for some time and then I manage to do it, then I get a better self-worth, it means something.
C.R.: Yes.

5.4.4 Joyful moments

P.T.: And I think with music therapy, that it is kind of a, it combines treatment and joy. It might be treatment, but at the same time it is also just joyful
Several: mhm
P.T.: It is not somebody coming into your room, putting medication in you or something
D.: (laughs)
P.T: it is something that makes you happy
C.R.: Yes
P.T.: I found that unique, I think that is absolute the positive in it
A.N.: Yes, me too.

One of the main things that the focus group outlined as unique to music therapy was the positive emotions and the joyful experiences that were facilitated through using music as a therapeutic medium. This was both related to music itself and to those experiences of mastery that musical engagement could promote. These joyful experiences where then further seen by the focus group as an important contributor for promoting and developing motivation in example breathing-exercises.

R.: How can this joy that you have talked about that music can create, how can that affect the music therapy processes with a person suffering from COPD?
P.T.: I am thinking that that is kind of the same as motivation (…) that the joy and the motivation is closely related to one another.

When considering that several of the focus group participants looked upon motivation as the main factor for a good rehabilitation-process, the close link between motivation and the joyful moments facilitated through music therapy was seen as an important contributor in the overall process of COPD-rehabilitation. Another aspect that must be highlighted when considering the importance of these joyful moments is the close link between happiness and life-quality (Næss, 1994, Ferrans, 1996, Oleson, 1990, both referred in Schirm, 2002) (see chapter 1.1). Even though the focus group participant did not explicitly link joyful moments with life-quality, it might be reasonable to think that the inter-relating relationship between resources, mastery and joyful moments found in the empirical material contributes to the promotion of an increased quality of life. The positive experiences of musical engagement was also something outlined by the COPD-representative stating: *I think it..I think it does you well, to sing.* The joyful experiences of music therapy were according to the focus group both related to the structural aspect of music such as rhythm and tempo, and to those expectations related the memories that were associated with the music.

A.N.: Something just happens when you listen to music, right, that you like. The foot starts moving and you feel like dancing and…
M.T.: And it is the memories attached to the songs (…) right, because then you have some expectations of having fun and yes.

The aspects outlined above might be linked with DeNora`s concept of the use of music for self-regulation and self-modulation (ibid, 2000). Several of her research informants spoke about how they used music for maintain or enhancing a preferred state and through the properties of the music, finding the music that was "works" for them in a situation (DeNora, 2000). But it was not only the general structure or properties of the music that made it "right" for the situation. Also previous association was seen as shaping the perception of the music (DeNora, 2000), an aspect that can be related back to the music therapist outline of expectations linked with the memories attached to the music in this thesis empirical material. The memories and association to music and the structural aspect (e.g. genre) was also seen as the two main factors for shaping the focus group participant's musical taste.

M.T.: You have some music that makes you happy and then you have some music that you really don't want to listen to.

In this discussion then, the focus group outlined that sensitivity of the client's musical taste and preferences was the most advantageous way for promoting joyful moments. Using the musical preferences of the client as a starting point for the music therapy sessions, can be linked with the cultural awareness seen in the resource oriented music therapy approach (Rolvsjord, 2004; 2008; 2010) and outlined in the ecological music therapy perspective (Stige, 2002).

5.5 Summary

To integrate music as a part of a holistic rehabilitation for people suffering from COPD, was looked upon as advantageous by the focus group participants. This was mainly due to the possibilities of the music therapy to use the client's musical story to enhance a ecological transitions from a patient to a person, a factor that strongly resonates with the focus group perception of a the concept holistic. This role-change was then further seen as an important contributor for increasing the acknowledgment on several layers in the client's surroundings. Being engaged and using musical engagement was also seen as a way of promoting opportunities for the client to experience mastery through using his resources. These experiences seemed further to promote self-worth, motivation and joyful moments which according to literature is crucial for the life-quality of a person (Næss, 1994, Ruud, 1997, Ferrans, 1996 & Oleson, 1990, referred in Schirm, 2002,Wormnes & Manger, 2005, Rolvsjord, 2008;2010).

5.6 Core category: Reciprocal relating

As discussed in chapter 5.1, reciprocal relating was a key theme used by the focus group used the word at several occasions to explain different processes of relating. The music therapist, related to how music therapy could be integrated in the COPD-rehabilitation outlined an example of this.

M.T.: The way I see it, it all cooks down to reciprocal information (...) that one is thorough with giving reciprocal information.
Several: Yes.

According to the focus group, reciprocity was closely related to development of mutual relationship in interdisciplinary collaboration and with the COPD-client. This link between reciprocal and mutual is also in line with Oxford Dictionary (2011) perception of the word reciprocal, which as an adjective refers to an action of binding each of two parties together in a mutual and equal relationship (Oxford Dictionary, 2011). The nature of the mutuality stated by the focus group though, seemed not to imply that everybody should be similar or alike. Rather they seemed to underline the differences and uniqueness of each member as the basis for creating mutuality in their collaboration. Why? Because the uniqueness of each member was looked upon as the starting point for the reciprocal knowledge-exchange that further could form the basis for the development of the collaboration towards establishing a holistic rehabilitation. In addition as the auxiliary nurse stated (see end of chapter 5.2.2.), through this process the staff could influence each other's work. The reciprocal process could thereby be broadened to not only referring to something that one comes into and stay in, but as something that implies evolvement and developing. This calls for the need to add mutuality's closely related word mūtāre meaning "to change" (Oxford Dictionary, 2011) to the understanding of a mutual relationship.

The concept reciprocal relating in the context of the empirical material can then be used to explain both a type of relationship that links parties together while also possibly change something through relating. As discussed in relation to the integration of music therapy, both the music therapist and the other member's working approaches seem to reciprocally change each other through their process towards establishing a holistic COPD-rehabilitation wherein music therapy took part. In addition, it was not only the professionals that seemed to change each other. Also the client and other people's perception of him, seemed to undergo some kind of changes, both through being perceived as an authority in the collaboration as well as in those processes that music therapy according to the focus group seemed to facilitate.

Reciprocal relating then looked to be linking all the categories together and describing the given nature of how the relationship between the themes and categories ought to be seemed. On an overall level reciprocal relating was also looked upon as a crucial springboard for a holistic COPD-rehabilitation to be developed and for music therapy to be integrated and be able to contribute in such rehabilitation.

6. DISCUSSION

PART I: HOW CAN MUSIC THERAPY BE PART….

Related to the discussions in chapter 2.3.1 and 2.3.2 interdisciplinary collaboration between the staff and the person suffering from COPD is considered highly important in order to create a holistic rehabilitation that address the complex needs of the client. According to the empirical material of this thesis, a focus upon interdisciplinary collaboration was also seen as crucial for the integration and maintenance of music therapy in a holistic rehabilitation of people suffering from COPD. Related to these aspects then it seems necessary to first of all construct a theoretical frame of how to integrate music therapy in an interdisciplinary collaboration, before discussing the profession's possible contribution in a holistic COPD-rehabilitation. Related to the reciprocal relating between the categories of the empirical material, it must be made explicit that the strategies for integration also seem to play a crucial role for music therapy's contribution in such rehabilitation.

6.1 How to integrate music therapy in an interdisciplinary collaboration

As mentioned in chapter 2.3.2 music therapist has for several decades underlined the advantages of working together with other disciplines to gain acceptance and support for their work and in order to develop music therapy within different context (Twyford & Watson, 2008a, Sutton, 2008). Collaboration is also important when considering the transdisciplinary nature of music therapy (Bruscia, 1998). According to Bruscia (1998), music therapy itself is "(…) a dynamic combination of many disciplines around two main subject areas: music and therapy" (ibid, 1998, p.6). Depending on the setting, the music therapist's work is therefore often informed both by knowledge from the musical field, namely sociology of music, ethnomusicology, music education and biology of music and the diverse traditions of the therapy fields, such as psychotherapy, healing traditions, recreation therapy and medical fields, to mention some (Bruscia, 1998). One way of gaining deeper insight into the fields to which the music therapist's work is informed, is to work in collaboration with the specific professions of these fields. As Magee (2008) states, "Joint working therefore offers music therapists a chance to acquire essential skills and knowledge base specific to the clinical area (…) (ibid, p.158).Through this knowledge-exchanging with other disciplines, the chances also increases for a more continuous care wherein the different and sometimes changing needs of the clients is addressed (Twyford & Watson, 2008a), which is crucial for people diagnosed with COPD **(**Gerardi and ZuWallack, 2001, Celli & McNee, 2004).

Working within a team also challenges the music therapist to find a balance between the uniqueness of the work and working in accordance with the team's common goals (Barrington, 2008). As Hedderly (2008) states: "Historically, there has been a need for music therapists and other arts therapists to maintain clear boundaries around our practice in order to establish and preserve the value and authenticity of our clinical work" (ibid, 2008,p.140). Although it might be difficult to find a solution to how music therapist should address this challenge, a growing number of music therapist see collaborative work as advantageous for accomplishing a consolidate role for music therapist (Twyford & Watson, 2008b). This might be related to the professions being more widely established, leading music therapists to feel more confident and use collaboration instead of isolation to define their roles and boundaries (Twyford & Watson, 2008b).

Based on the idea that the context wherein the music therapy takes place seems to heavily influence how it is defined (Bruscia, 1998,Barrington, 2008), working in a interdisciplinary team might also to impact how music therapy is defined and what it has to offer. Even though this makes it difficult to draw the boundaries of what music therapy is, defining music therapy in collaboration with others might also be advantageous by the fact that it might help music therapist to gain more diversity in his approaches.

Related to empirical findings and literature, this diversity seems particularly important when working with people suffering from medical, chronic diseases such as COPD, related to their complex needs and changing medical state. According to Jochims (2004) being flexible enough to switch between what she names as "experience-oriented" and "exercise-centered" approaches is considered highly important to address the client's changing need and increase quality of life (Jochims, 2004). It must be made explicit that Jochims article (2004) is written in the context of neuro-rehabilitation, wherein clients experience a sudden shift in life when becoming chronically ill. Even though COPD is also a chronic disease, it seems to be more in line with a regressive disorder considering that the illness evolves through different stages (Johannesen, 2009). Still, diversity in approaches seems also to be necessary in relation to COPD-clients. An example of this flexibility is Engens` research findings (2005) suggesting that preference-based singing both increased the functionally outcome and the life-quality of the person (see chapter 2.2). In the empirical material this was also stated by the focus group-participants highlighting the importance of the music therapist to be in dialogue with the staff and the client about the client's medical state in order to work in accordance with the capacities of the client. The flexibility in approach can also be related to the resource-oriented music therapy approach, stressing the balance between working with the resources and the symptoms and the resources of the client (Rolvsjord, 2008).

When working in accordance with the client's needs and possible goals, it will also be important for the music therapist to make explicit to his or her team how he or she work in order to address them (Magee, 2008). This might also increase the acceptance and understanding of how music therapy might contribute in the overall rehabilitation-program of the client. At the same time, working goal-oriented might be challenging for a professions such as music therapy which mainly has it's focus upon processes and relationship-development (Magee, 2008). A strategy for meeting this challenge is to understand the team and the client's expectation to music therapy and plan the session according to these (Magee, 2008). Even so, according to the informants of the focus group though, it was considered a challenge to have any expectation of how music therapy might contribute to people with COPD if they were not give insight into the music therapist's assessment first. This lack of insight and experience of music therapy might have a huge effect on the expectation towards it, both for the client and the staff. Considering the strong impact that especially the client's expectation in a treatment or a rehabilitation seems to play upon the outcome of therapy, (Wampold, 2001, Messer & Wampold, 2006, Rolvsjord, 2010)[30] for the client to gain insight what music therapy possible have to offer might then actually play

[30] This statement is related to the Common Factor-approach in psychotherapy which demonstrates a shift from the medical model of psycotherapy suggesting that specific ingredients belonging to a particular therapy is what makes the therapy work. Rather contextual factors common to all psychotherapeutic models such as therapist-client alliances, client`s expectancies (also called the "placebo-effect) the client`s use of the therapy and the effect of the therapist is seen as important in order to understand what makes therapy work (Wampold,2001,Messer & Wampold, 2006, Rolvsjord, 2010).

an important role for music therapy's degree of contribution which might further affect the acceptance and maintenance of the discipline within the COPD-rehabilitation.

How then should a music therapist work to inform the client and increase the other team-members` insight into his or her work? When working with the client, it is important that the music therapist in the beginning of the process informs about his or her role and explains why the client is offered music therapy (Dileo, 2000). During the process the music therapists should make explicit to the patient why he or she selects specific methods (Dileo, 2000). The importance of involving the client in forming the process must also be added so that he can feel ownership to it. In relation to increasing colleague's knowledge about the music therapists assessment, the most common way might be to verbally communicate the work in a language balancing between the unique processes music therapy can facilitate, while at the same time focusing on the common goals of the client. Another, and more authentic way, is to include the staff in the music therapy. According to the focus-group members, direct observation of the music therapy work, was seen as a way of gaining a deeper understanding into those processes which is hard to translate into words. By watching the music therapist's approaches they also found it easier to integrate them into their own work. In this way, the approaches of the music therapist are influencing the work of the team while at the same time being influenced by the team. This leads to a reciprocal process of sharing, influencing and shaping each other's techniques, not only acknowledging the "difference branches of knowledge" (Oxford Dictionary, 2011) but also letting the approaches impact and inform the work of each professions.

Related to the ecological approach of this thesis it is also relevant to relate music therapy's integration in a holistic COPD-rehabilitation to the social and political trends in our society. It seems though that the ongoing shift in the healthcare services from a disease and symptom model into one of prevention and wellness (Hanser, 2010) actually has created an opening for music therapy to be accepted and valued as part of an interdisciplinary team. As Hanser (2010) states:

> (…) integrative medicine provides a new way to the emotional and spiritual need of patient in addition to the physical (...) This emerging field has redefined the service of medicine and built an infrastructure to support the use of music (…) (Hanser, 2010, p.851).

PART II: ….IN A HOLISTIC REHABILITATION FOR PEOPLE SUFFERING FROM COPD

6.2 "Music sets things in motion"

The headline for this chapter is a statement from a COPD-client that I worked together with in my practicum-period this autumn.[31] It must be made clear that he stated this in one our sessions where he was able to "loosen up his phlegm from the lungs" through singing, thus pointing towards a physical aspect of how music could be helpful. Even so, I felt that this statement could be used as a metaphor for the possibilities of music therapy to facilitate a positive movement related to identity, acknowledgment, resources, mastery and motivation as seen in the empirical material and in literature (Ruud, 1997;1998, Rolvsjord, 2004;2008;2010, Raskin & Azoulay, 2009).

Related to the research question upon how music therapy can take part in a holistic rehabilitation for people suffering from COPD, a main aspect of the focus group perception was how musical engagement could fostered the process of "uncovering" the person behind the patient" which was looked upon as a main perception of how a holistic rehabilitation ought to be. The empirical material thereby seem to point towards some possibilities in the use of music to facilitate movement in a person and his surroundings from "a patient who can´t" to a "person who is competent". This seems to point towards core-aspects of the therapeutic possibilities of empowerment and agency enhanced in a resource-oriented music therapy approach (Rolvsjord, 2004).The starting point for this movement to begin though seemed in the empirical material to be an ecological awareness of the client's musical preferences and cultural background. Facilitating opportunities wherein the client could use his musical interest seemed to be a way that the client could affect his surroundings through creating acknowledgement on several ecological layers (see chapter 5.4.2). Even though the COPD-representative did not state that the life-situation was improved because of this, on a more general level, the experience of having a voice and having the power to improve one's life-situation, seems to be closely related to the concept of agency, autonomy and the facilitation of increased self-efficacy and life-quality (Wormnes & Manger, 2005) which are all considered strongly important in COPD-rehabilitation (Garrod, Marshall & Jones,2008).

[31] It is important to inform that this is another COPD-client than the one in the focus group-interview.

6.3 The Musical Story as a Personal and Social resource of growth

If being involved in music generally strengthens our sense of identity and if having a strong and differentiated sense of identity is connected to an higher quality of life, then it follows that music contributes to health in general (Ruud, 1998, p.66)

In this statement, Ruud (1998) draws both on Antonoskys salutogenetic research into how and why we maintain health (1991), psychologist Næss four concepts of quality of life (Næss, 1994) and his own research upon music and identity (Ruud, 1997). Based on this, Ruud (1998) links musical engagement with experiences of vitality (awareness of feelings), agency, belonging and meaning (ibid, 1998, p.57). Related to the cultural status that music has, to be engaged in music can also promote feelings of mastery and an experience of being competent (Ruud, 2008), which is seen as one of our basic human needs (Ryan & Deci, 2000). Facilitating experiences of mastery can thereby have an impact in the client's life beyond the music therapy sessions. Wormnes & Manger (2005) suggest that experiences of mastery can function as personal reminder of being "capable" and be used as a "treasure-box" to address future problems and challenges: "The trademark "I can" appears more and more automatic (…) and promotes empowerment, and a feeling of happiness, energy and self-confidence arises" (Wormnes & Manger, 2005, p.68, own translation). This is also demonstrated in the empirical material, wherein the doctor outlines how important it is to experience that "I can" as she stated, for the fostering of self-worth (see chapter 5.4.3, p.61). And as she further stated, to integrate music therapy in the COPD-rehabilitation could implicate the fostering of mastery-experiences with the COPD-clients.

If being in engaged in music can promote feelings of identity, mastery, self-confidence, happiness and growth as seen in the empirical material and literature, then facilitating opportunities for the client to have access to use music will be an important factor. Several authors have outlined that music and musical engagement seems to be a human capacity that we all are born with (Blacking, 1973, Trevarthen & Malloch, 2000, Dissanayake, 2001). According to Small (1998) the musical industry of today's society with it`s perception that only a talented few is empowered to produce music, has hijacked and robbed peoples right to use their own, inhered musicality (p.8). To be able to use and be engaged in music thereby becomes a social resource to which some people do not have access. To work towards the client re-gaining "power-over" and "right-to" using music is thereby seen as an important aspect in a resource-oriented approach and can be linked with Rolvsjord`s term "musical empowerment" (2004) "(…) defined as process of regaining rights to music." (p.107). When given the opportunities to be engaged in music, music can be a health-resource both on an individual and on a social and structural level (Rolvsjord, 2008, 2010). This has clear relation to the outline of the COPD-representative in the empirical material wherein he illustrates how he used music therapy as an opportunity to play on his accordion again, which on a social level created acknowledgement and awareness of his identity both for himself and his surroundings.

But, as stated in chapter 6.2, the starting point for the "movement of music", was awareness and acknowledgment of the client's own relations to music. An awareness and sensitivity to the type of music the client (and sometimes the therapist) can among others be linked with an interactional perspective seen in personality psychology.[32] This perspective might also be representative for the musical choices of a person (Rentfrow & McDonald, 2010) "(…) And just as individuals seek out and create environments that satisfy their basic psychological needs, so too might they seek auditory, or musical, environments that reflect and reinforce aspects of their personalities" (Rentfrow & McDonald 2010, p.674). This statement is related to a literature-review about research concerned with exploring the relationship between personality traits and music preference. Rentfrow & McDonald (2010) at the end concluded that all the research reviewed indicated clear connections between musical preferences and personality (ibid, 2010). Given this strong link that exist between musical preferences and personality underlines the important of not only being aware, but also acknowledge and use the musical preferences actively in the music therapy. This might be especially important in clinical work with COPD-clients who many might experiences loss in identity. Using the client`s musical preferences can thereby function almost like an "identity-information-channel" or what Ruud (1998) names "a soundtrack of life":

> Each sound carries traces of history (…) It may help structure our autobiography by punctuating and binding together significant life-events. It may contain leitmotifs that signal broader cultural formations and ideologies, personal character, values and life-styles (ibid, 1998, p.92)

An approach to music therapy that is concerned and sensitive to the client's cultural background, especially in relation to music, can thereby function as a facilitator for the client to explore his "musical life-soundtrack" (Ruud, 1998). In an ecological perspective this might also influence the environment of the client through increasing their awareness of the client's personal identity and cultural background, factors that are considered as important strategies for reducing stigma (Saylor, Yoder & Mann,2002). Considering the strong impact that stigma imposes on a person with chronic illness, Saylor, Yoder & Mann (2002) states: "(…) reducing the impact of stigma are as crucial as those that reduce blood pressure or chronic pain" (p.63).

[32] In an interactional perspective it is suggested that individuals selects and creates social and physical environments that reinforce and reflect elements of their personalities, self-views and values (e.g Buss, 1987, Gosling, Ko, Mannarelli & Morris, 2002, Swann, Rentfrow & Guinn, 2003,Rentfrow, Gosling & Potter, 2008, all referred in Rentfrow & McDonald, 2010).

6.4 Musical engagement creates joyful moments

As discussed in chapter 6.1, music therapy is influenced from several fields, and promotion of agency, mastery, identity building and empowerment is thereby not a unique contribution only achieved through music therapy. One might thereby ask, is there a uniqueness of using music as a therapeutic medium in the COPD-rehabilitation? According to the empirical material, the joyful moments of musical engagement might be a key to finding music therapy's uniqueness.

The positive emotions and the joyful moments outlined by the focus group are also supported by Rolvsjord (2008) who links these experiences with the use of one's resources in the musical engagement. She thereby makes explicit that to use one's strengths and experience mastery does not only have an impact on the problems or the symptoms, but must be seen as a value in itself. Based on research in positive psychology that underlines the importance using one's so-called "signature strengths" to experience joy and happiness (Seligman, 2003;2005,referred in Rolvsjord, 2008), Rolvsjord proposes that this might be the most important source to the joy we experience through music making (ibid, 2008).

One can then further ask, how might these joyful experiences through musical engagement make a contribution in a CODP-rehabilitation? One of the main factors in my empirical findings was related to how these positive experiences, especially when using preference-based music, facilitated motivation in the music therapy-session and also when using music in other activities during the day. According to empirical findings and literature, motivation is considered a key aspect of rehabilitation-outcome in general (Colombo et.al, 2007) and the facilitation of this in music therapy might be of high contribution in the overall COPD-rehabilitation. This perception is also supported by Raskin & Azoulay (2009) related to how motivation may support the coping of the illness. In addition, the link between happiness and life-quality (Næss, 1994, Ferrans, 1996, Oleson, 1990, both referred in Schirm, 2002) might imply that fostering of positive emotions in music therapy can decrease the depression and low life-quality that COPD-clients tends to suffers from (VanEde, Yzermans, Brouwer, 1999, Gore, Brophy & Greenstone, 2000, Ståhl et.al., 2003, Miravitlles et.al, 2004, referred in Miravitlles, 2007, Fan et.al, 2007).

The qualities of the joyful experiences of musical engagement are also described by Rolvsjord (2010) related to how a young girls positive emotions of singing was involved in finding motivation and interest. The experiences where related both to finding a hobby, something to do in her leisure time at the hospital and in her general coping-struggle. Music therapy made her feel better "(…) was lightening up her mood and thus gave her some sense of hope, motivation and meaning in life" (Rolvsjord, 2010, p.114). Even though Rolvsjord`s (2008) experiences are written in the mental-health context, it is reasonable to think that these aspects also is seen as valid in the context of COPD-rehabilitation.

This perception is supported by Raskin & Azoulay (2009) that states:

> Music therapy may also support coping with chronic illness as it motivates patients to engage in treatment through creative outlets that address relevant psychosocial needs while influencing breathing directly (ibid, 2009, p.69)

Thus music therapy is seen as way to create engagement and address both psychosocial and physical needs, pointing towards the concept of holistic treatment. In the empirical experience described in the introduction, Tove reported that one of the important impacts of music therapy was that it brought joy to her life. This made her want to use music rapidly in her breathing exercises, creating a positive spinal both related to physical aspects, such as better breathing and psychosocial aspects such as increased life-quality. Feedback given by COPD-clients participating in the Music for AIR programme at Louis Armstrong Center for Music and Medicine seems to support Tove`s experiences:

> Patient's feedback has been positive and the music therapy adds a unique component and motivating way to learn how to breathe optimally. Patients appear motivated and challenged to use their own creativity in managing their disease (Raskin & Azolulay, 2009, p.80).

The latter aspect upon creativity might be an important argument for why music therapy should be integrated in the COPD-rehabilitation. The reason for this is that it touches right at the critical point of how a rehabilitation of chronic illness should be developed.

> To date, society defines *illness* and *debility* largely with a disease- specific focus. This model places chronically ill individuals at a disadvantage. Rather than seeking cure of disease, the chronically ill person needs to be considered as "modified" rather than "nonproductive." Such a perspective leads to maximization of well-being, creativity and productivity (Lubkin & Larsen, 2002, p.13).

7. CONCLUSION

In line with the overall intentions of grounded theory, the conclusion of this thesis will be used to draw a picture illustrating how the empirical material have constructed the substantive theoretical perspective concerning how music therapy can be part of a holistic COPD-rehabilitation. In line with the experiences of being in this process, I have chosen to use a metaphor from nature to illustrate the growth of the substantive theoretical perspective that emerged from the data.

7.1 The three seeds

How can Music Therapy take part in a holistic rehabilitation for people suffering from COPD? The road that has been walked for exploring this question has been long and consisted of several stones necessary to build the road further. Fortunately the road has not been walked alone. Rather, it has been collaboratively explored with a COPD-representative and several professions who also have worked as guides for the selection of literature. Through this collaborative journey of exploration, three main seeds emerged.

One being the need for a holistic rehabilitation informed by an overall ecological framework, the second being the importance of involving the COPD-client himself in developing the holistic rehabilitation and the music therapy-offer integrated in this. The third seed was the necessity for music therapist to work in an interdisciplinary collaboration in order to increase ones flexibility and to gain acceptance in the team.

7.1.1 The seed of holistic COPD-rehabilitation

Throughout the whole process of this research, one aspect that has continued being highlighted both by the focus group participants and in literature is the necessity of moving from a physical treatment focus towards a holistic rehabilitation for people suffering from COPD (Gerardi & ZuWallack, 2001,Hanger, 2007, Kunik et.al.2005, Helse- og Omsorgsdepartementet, 2008). This is especially due to the complex nature of COPD and the regressive development of the disease, changing the need of the client almost at a daily basis. In addition, a close relationship between the perception of holistic and ecological is outlined both in literature and in the empirical material related to a focus upon seeing the client as a whole person rather than just focusing on his diagnosis. The overall ecological framework is also related the ecological causes of COPD such as smoking and air-pollution, making the illness being socially perceived as self-inflicted, a factor that seems to increase the stigmatizing effect and the de-prioritizing (Saylor, Yoder & Mann, 2008, Dager, 2009). An ecological perspectives that takes into account how the interaction between the social layers around the COPD-client influences the development of the illness and the identity of the client, is thereby necessary as an overall framework for a holistic COPD-rehabilitation.

It is important to make explicit that the ecological perspective does not only focus upon how the social layers influences the person. Rather there is an inter-relating understanding of how the person and his surroundings influences and changes each other reciprocally (Bronfenbrenner, 1979, Bruscia, 1998, Stige, 2002, Ruud, 2008). To let the ecological perspective inform the holistic rehabilitation then implies a focus upon how the clients` actions in the rehabilitation can influence and change the social layers of his surroundings. An empirical findings from this thesis was the outline of how music therapy seemed to foster acknowledgment of the COPD-client on several levels of the client's surroundings, changing the staff's perception of the client (see chapter 5.4.2.).

Several other empirical findings also implied that music therapy was looked upon as advantageous to integrate in a holistic rehabilitation. This was mainly due to the processes enhanced through music therapy that were seen as standing in close relationship to the aspects of holistic rehabilitation and the ecological perspective. One of the main factors was how music therapy could promote a movement in roles from patient to person through the use of the client's musical preferences. As discussed above, this seemed to foster acknowledgment on a social level.

On a personal level, music was looked upon as a resource that when being used in music therapy, could give the COPD-client experiences of mastery, empowerment, agency and joyful moments. These experiences could promote life-quality and motivation, awaken the memories of the person's resources and competences (Manger & Wormnes, 2005) and promote a type of ecological transitions (Bronfenbrenner, 1979) moving from the "sick role" (Parson, 1951, referred in Lewis and Lubkin, 2002) of a patient who can't towards a person who is competent.

7.1.2. The seed of user-involvement

Mutuality and reciprocity seemed to be key words used by the focus group and in literature for describing how user-involvement ought to be both in order to foster empowerment, increasing the perception of agency and autonomy and improve life-quality (Ruud, 1998, Kohler, Fish & Greene, 2002, Saylor, Yoder & Mann,2002, Rolvsjord, 2004, Reeve, 2005,Wormnes & Manger, 2005, Arnold et.al, 2006). When considering that autonomy has been defined as a basic human need (Ryan & Deci, 2000), the function of user-involvement as a provider of opportunities[33] for increased autonomy and agency is crucial. This is also supported by Hummel (2002) stating that one way to restore client's power and reduce their vulnerability, is to give the client insight into the nature and meaning of their illness (Hummel, 2002). This also resonates with Johannessens` outline of the necessity of giving the COPD-client knowledge in order to take responsibility in his own rehabilitation and to immerse the evolvement of the illness (Johannessen, 2003, 2007, 2009).

In relation to the thesis focus upon holistic COPD-rehabilitation, user-involvement tends to be seen in nursing as a natural part of holistic nursing (Nelson, 1988, referred in Hummel, 2`002**).** The link to holistic rehabilitation can also be related to how the increased agency enhanced through user-involvement can strengthen the self-worth, increase the awareness of the client`s competence and reduce the stigmatizing effect of perceiving the person not just as a patient (Saylor, Yoder & Mann, 2002). This strongly resonates with the holistic and ecological perception of the focus group upon seeing the patient as a person. To put the client in the center of the rehabilitation was also looked upon by the focus group as the most advantageous way for developing a holistic rehabilitation addressing the client's complex and changing needs. The reciprocal aspect of user-involvement in such rehabilitation was described by the focus group as a situation wherein the profession learned from the client at the same time as the client learned in example breathing techniques from the staff that he could use by himself in his everyday life.

[33] The reason for using the phrase "provider of opportunities" is due to the importance of being sensitive towards the clients` own choice of the degree of autonomy. Forcing the client to take on the role as an agent in their life, might actually a way of decreasing their autonomy. Rather they should be given the opportunity to choose their role themselves.

In music therapy with COPD-clients this could be outlined through acknowledging and learning about the way the client have used and uses music (Rolvsjord, 2004, Stige, 2002) and through the music therapist giving the client knowledge about breathing techniques that he can use for singing or playing these songs again.

7.1.3. The seed of interdisciplinary collaboration

Interdisciplinary collaboration was seen as crucial by the focus group participants in order for music therapy to be integrated and contribute in a holistic COPD-rehabilitation. This was both due to the necessity of developing flexible approaches in order to increase the other professions` understanding of music therapy (Twyford & Watson, 2008a) and to address the client's complex and holistic needs (Jochims, 2004, Twyford & Watson, 2008a). The latter aspect of flexibility was also looked upon as one of the advantageous of music therapy in a holistic COPD-rehabilitation, related to the opportunities of both addressing social, psychological and physical factors at the same time. This is also in line with a resource-oriented music therapy approach, wherein the necessity of addressing the needs of the whole person, both his symptoms and resources are highlighted (Rolvsjord, 2008).

On a more general level, interdisciplinary collaboration was seen in literature and in the empirical material as necessary for the establishing of holistic rehabilitation (Remsburg & Carson, 2002, Helse- og Omsorgsdepartementet, 2008, Celli & McNee, 2004). In order for interdisciplinary collaboration to be developed and maintain though, the structural aspect of how this collaboration ought to be emerged as an important topic in this thesis, wherein *mutuality* and *reciprocity* seemed to be a key words. This topic then is a reminder of the importance of focusing not only on the team's function and contribution, but also upon the qualities of the relations between the team-members when establishing an interdisciplinary rehabilitation-team wherein music therapy is integrated.

7.2 The core category: Reciprocal relating – The foundation of growth

The seeds needed to build a holistic COPD-rehabilitation wherein music therapy takes part seem to originate from the foundation of *Reciprocal relating.* The core category of reciprocal relating between the professions and between the professions and the COPD-client, emerged through the empirical material to be the requirement for the development, establishment and maintaining of an interdisciplinary collaboration needed in order to move towards a holistic and ecological COPD-rehabilitation. It was also the foundation needed for music therapy to be integrated in such rehabilitation, because reciprocal relating with the other team-members and the client increased the flexibility and knowledge of the music therapy and made it easier for the other professions to gain insight into music therapy.

As discussed in chapter 5.6 reciprocal relating could also be used to describe a process of evolving changes, and both the music therapist and the other member's approaches seemed to reciprocally change each other through their process towards establishing a holistic COPD-rehabilitation wherein music therapy took part. The changing factor of reciprocity is also present in an ecological perspective (Bronfenbrenner, 1979, Bruscia, 1998, Stige, 2002, Ruud, 2008) and was demonstrated in the empirical material in the sub-categories underneath the main category of music therapy and COPD. Here the focus group outlined how the perception of the client changed both to himself and among the staff through increased acknowledgment enhanced through increased identity, experiences of mastery and joyful moments creating opportunities for motivation, growth and increased quality of life. These changes seemed further to have an impact upon the aspect of user-involvement and to the holistic and ecological perception of seeing the patient as person.

The latter aspect points towards the function of reciprocal relating also as the aspect linking all the categories together and describing the nature of how the categories was relating to one another. The core of this type of relating was found between the main categories of holistic rehabilitation and music therapy and COPD. As already discussed, music therapy was seen as advantageous to integrate in such rehabilitation due to the holistic processes of "uncovering the person behind the patient", that it enhanced. In order to work in a holistic manner though a broad knowledge was needed for addressing the complex needs of people suffering from COPD. To broaden this knowledge, reciprocal relations with an interdisciplinary team was necessary. Reciprocal relations to the rest of the team was also necessary for the other staff-members understanding of music therapy, an understanding that could increase the changes for music therapy to be integrated and maintained in the holistic COPD-rehabilitation.

How can music therapy be part in a holistic rehabilitation for people suffering from COPD? Well, the end of the road has yet to be reached, but a clearer perception of where to start and which direction to go, can be said to have emerged through reciprocal relations between a COPD-representative, a doctor, an auxiliary nurse, a physiotherapist, a music therapist and myself. The empirical material suggested that for music therapy to be part of a holistic rehabilitation for people suffering from COPD, ongoing processes of collaborative, reciprocal relationships between the music therapist, the client and the other professions are crucial. To let the empirical material guide the way further, I will conclude with a statement from the focus group, wherein a illustration of how reciprocal relating through dialogues is necessary in order for a holistic COPD-rehabilitation to develop and for music therapy to be integrated:

MT: *I also see that the focus you have upon music therapy as holistic treatment is totally necessary because no professions can do it alone…so that the holistic, dialogue-based way of thinking are the central core for succeeding.*

7.3. Critique

As discussed in the method-chapter related to time-aspect, amount of data collected and my research-experience made it challenging to generate a substantive theory (see footnote 17, chapter 3.2.2). The challenges of generating a theory were also due to the ability to reach theoretical saturation in order for a theory to be generated. As Amir (2005) states: "The beginning researcher often does not have the research judgment to know when the data are theoretically saturated (…) (p.376). The challenge of reaching theoretical saturation is also supported by Robson (2002) who describes: "It may be difficult in practice to decide when categories are `saturated`, or when theory is sufficiently developed" (ibid, 2002, p.192). Related to my own research-process, the decision of ending the analysis might have been more due to lack of experience and time-aspect than to me feeling that the data-material were saturated (see chapter 3.2.2). Because of the discussed aspects, this study must thereby be viewed as modified grounded theory-study and the data-result emerging from my study is then a substantive theoretical perspective closely intervened with the context wherein it was studied and limits the generalizations of the results. This decision is also in line with a general critique raised against the originally intensions of grounded theory to generate a theory (Thomas & James, 2006). This critique might be especially related to the method's placement in a qualitative research wherein the belief upon truth as something produced by human being related to their experiences in a context is dominating (Ashworth, 2008). It is also in line with the post-modern era oppositions of the traditional *representationalism* referring to belief that there can be a fixed or determinant relationship between words and the world (Gergen, 1994). In a the post-modern era it is rather stated that theories are reconstructed and deconstructed in relation to the shifting context and that words can never represent the world by it's whole (Gergen, 1994, Amir, 2005, Asworth, 2008). Thus, the emerging substantive theoretical perspective of this thesis can then be understood as a suggestion of how *step one* of music therapy's part-taking in holistic COPD-rehabilitation might be constructed.

The decision to construct a substantive theoretical perspective was also due to the overall philosophy of the venue where this research took place. Bergen Red Cross Nursing Home, is a institution which is colored by the hospice-philosophy of the Red Cross which "(…) assure that all patients and their relatives are looked after in relation to physical, psychological, social and spiritual challenges and needs" (Bergen Røde Kors, 2010) The overall philosophy of "Bergen Red Cross Nursing Home" seems to have clear parallels to the holistic view of rehabilitation wherein one through collaboration work, focus upon the person as a whole. Thereby, the participants, especially the professions-representatives, might have been influenced by this philosophy through already having a positive attitude towards holistic rehabilitation. This might also the case for me considering that I have had two practicum-periods at Bergen Red Cross, one before and one during the research.

This possible positive trend towards holistic rehabilitation before the research project started, thereby makes it necessary to take into account the context wherein data-collection and analysis were carried out when reading the final results.

Another aspect in relation to the participants was the sudden shift in doctor-representative causing the new representative to not receive the informed consent prior to the first interview, which might have influenced her participation. In relation to the importance of assuring that all participants have been fully informed about the study prior to the data-collection (Dileo, 2000), this might also be seen as a fraction in relation to ethical concern. A possible reduction of this risk was related to the doctor's broad experiences of participating in both quantitative and qualitative research-projects and her broad knowledge about COPD. She also had experiences from music therapy with Tove, the COPD-client described in the introduction.

Critiques of the grounded method have also been raised related to the degree to which a researcher is able free oneself from prior theory and preconceptions, when analyzing the data to generate his theory (Robson, 2002, Thomas & James, 2006). This critique has clear links to my role as a researcher when thinking about my prior experience with the COPD-patients and my readings upon music therapy and COPD and COPD in general. This is also seen in relation to my choice of venue for conducting the research that was both based on my prior experience with music therapy in relation to COPD and more the practical factor of situating the project at the same place as my ongoing practicum took place. My prior experience with the COPD-client might thereby have influenced my neutral role in the research process. Even though I try to focus on my self as a neutral moderator in the group, the fact that I was a music therapist might have lead the participants to feel that they could only speak of music therapy in a positive manner. This feeling could also be amplified by the fact that one of the participants was a music therapist. In addition, both the doctor who had the former medical responsibility for Tove and the COPD-representative had experiences with music therapy that might have influenced how she spoke about music therapy. These aspects combined with the relationship I had to the staff and the COPD-representative at Bergen Red Cross Nursing Home, might also have influenced the openness in the focus group. In addition, critique in relation to group dynamics and power-hierarchy that might exist within the focus group (Robson, 2002) must be taken into account as a factor that might have affected the participant's perceived feeling of speaking freely within the group. The group dynamic might also influence which participants that talks (Robson, 2002) that might have caused the discussions being formed more by particular participants than others. This might have lead to some themes being left unspoken.

7.4. Implications for further research

In line with the aspects of critique discussed, several implications for further research must be made explicit. First, due to time aspect, lack of research-knowledge and amount of empirical material, there is a need for conducting a research-project over a longer period of time and collecting data from several contexts. The latter aspect is also related to possible bias of positive attitudes towards holistic rehabilitation in terms of the overall philosophy influencing the research-site wherein this data-collection was outlined. In addition, the fact that some participants already positive experiences with music therapy makes it necessary to conduct research in contexts wherein music therapy is not yet part of the environment.

In an effort to broaden the music therapy-offer to people suffering from CODP, it would also be advantageous to conduct the research both at in-patient and outpatient - services. In order to gain a deeper insight into how COPD-clients themselves can make use of music therapy, it would thereby be advantageous to collect data from both an interdisciplinary focus group with a COPD-representative at an in-patient service in example at a hospital and from COPD-clients at the outpatient service, either through group- and/or singular-interviews. I would further suggest that if music therapy is going to have a chance of being integrated into the growing focus upon holistic rehabilitation for COPD-patients, further research should be either mixed methods or pure qualitative research that contributes to present diversity and nuances (Malterud, 2008). In that way more of music therapy's possibilities in the holistic rehabilitation of people suffering from Chronic Obstructive Lung Disease may be uncovered.

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Appendix 1: Ethical apply to the Regional Committees for Medical and Health-related Research Ethics (REK).

ETISK KLARERING MED REGIONALE KOMITEER FOR MEDISINSK OG HELSERELATERT FORSKNINGSETIKK (REK)

1. Generelle opplysninger
a. Prosjekttittel:
En kvalitativ studie av hvordan musikkterapi kan inngå som en del av en helhetlig behandling for kolsrammede.

b. Vitenskapelig tittel
Utfyllende/faglig/engelsk hvis aktuelt
Musikkterapi som en del av en helhetlig behandling av kolsrammede
Music Therapy as part of an holistic treatment for people with Chronic Obstructive Lung Disease (COPD)

c. Prosjektleder

Navn	Simon Gilbertson
Akademisk grad	Associate Professor
Klinisk kompetanse	Music Therapy
Stilling	Associate Professor Music Therapy
Hovedarbeidsgiver	University of Bergen
Arbeidsadresse	Lars Hillesgate 5
Postnummer	5800
Sted	Bergen
Telefon	45248980
Mobiltelefon	45248980
E-postadresse	simon.gilbertson@grieg.uib.no

c. Forskningsansvarlig
Forskningsansvarlig er: Universitetet i Bergen ved Simon Gilbertson

2. Prosjektopplysninger

a. Prosjektomtale

Forskningsstudien skal resultere i en avsluttende mastergradsoppgave ved master i musikkterapi ved Universitetet i Bergen våren 2011.

Hensikten med studien er å utforske og diskutere, i en fokusgruppe med ulike fagprofesjoner, samt pasientdeltaker, hvordan musikkterapi på en generell basis kan inngå i en helhetlig behandling av kolsrammede. Bakgrunn for utforming av fokus er basert på masterstudentens egne praksiserfaringer samt studier av forskningslitteratur som belyser hvordan musikkterapi kan bidra i forhold til kolsrammede.

Fokusgruppen vil bestå av en fysioterapeut, en musikkterapeut, en sykepleier, en hjelpeleier og en pasientdeltaker. Utvalg av deltakere er basert på et ønske om å bygge opp et musikkterapitilbud som er basert på kunnskap fra ulike fagfelt og bruker selv for å på best mulig måte kunne sikre et helhetlig tilbud for mennesker rammet av kols. Et fokus på helhetlig behandling, hvor ulike fagprofesjoner samt bruker selv bidrar til å forme et behandlingstilbud, er også i tråd med politiske føringer i Helse og Omsorgsdepartementets Samhandlingsrapport fra 2008

b. Hvordan skal resultatene av prosjektet presenteres?

Resultatet av prosjektet vil bli presentert skriftlig gjennom studentens masteroppgave.

Anonymiseres opplysningene før de utleveres til prosjektet? Ja.
Opplysningene vil bli gitt koder som tilsvarer deltakernes profesjonelle tittel. Dette kan endres dersom deltakerne ønsker å være personifiserbare.

Redegjør nærmere for hvilke opplysninger det gjelder og hvordan de samles.

I dette forskningsprosjektet vil det ikke bli samlet inn noen form for personlig eller sensitive informasjon om deltakerne. Dataene samles inn gjennom fokusgruppeintervjuer som blir tatt opp på bånd og slettet ved prosjektets slutt (16.mai 2011).

De innsamlete opplysningene vil være

Avidenitifiserte

Samtykke

Gjelder både allerede registrerte og særskilt innsamlete opplysninger

Skal det innhentes samtykke fra dem opplysningene gjelder?

Ja

Redegjør nærmere for informasjon og samtykke

Alle deltakerne vil i forkant av studien motta et informasjonssamtykke som skal signereres. Samtykket er vedlagt denne innleveringen.

c. Varighet

Prosjektstart dato: Uke 40/41

Prosjektslutt dato: 16.mai 2011

Redegjør for hva som skal skje med prosjektdata etter prosjektslutt:
Alle lydopptak vil bli slettet etter prosjektets slutt. Masterstudentens egne notater vil bli oppbevart innelåst

3. Begrunnelse for spørsmål om framleggingsplikt

Begrunn hvorfor det er reist tvil om hvorvidt prosjektet må godkjennes av REK:
Hovedintensjonen med denne studien er å lære mer om mulighetene for fremtidige behandlingstilbud for denne populasjonen og det er derfor nødvendig å spørre en pasient om å delta, ikke som mottaker av terapi eller behandling, men som en signifikant informant i forhold til brukerperspektivet. Selv om masterstudenten i prosjektet involverer en pasientrepresentant, vil rollen til denne representanten være som en deltaker i fokusgruppen. Prosjektet vil derfor ikke beskrive eller omhandle noen form for behandling/terapi med denne pasienten.
Prosjektets fokus på utforsking av musikkterapiens generelle bidrag i en helhetlig kolsbehandling, bidrar til at pasientdeltakerens rolle i fokusgruppen primært vil bli som en generell representant for målgruppen.
Siden dette studie inkluderer en klient representant, ønsker vi å få mer informasjon i forhold til om studien krever en søknad for full etisk avklaring.

4. Vedlegg
Informert samtykke Last opp vedlegg

Dr. Simon Gilbertson
Associate Professor, Music Therapy
The Grieg Academy
University of Bergen
Postbox 7805
5020 Bergen
Norway

From: "post@helseforskning.etikkom.no" <post@helseforskning.etikkom.no>
Date: September 8, 2010 1:36:36 PM GMT+02:00
To: Simon Gilbertson <Simon.Gilbertson@grieg.uib.no>, Simon Gilbertson <Simon.Gilbertson@grieg.uib.no>
Subject: Bekreftelse på innsendt Framleggingsspørsmål

Framleggingsspørsmål: Musikkterapi som en del av en helhetlig behandling for kolsrammede.
Prosjektleder: Simon Gilbertson

Framleggingsspørsmål er mottatt i SPREK og gjenfinnes på prosjektleders liste over innsendte skjema.

For prosjektsøknader og biobanksøknader, kan innsendingen angres fram til førstkommende søknadsfrist.
Denne kvitteringen kan derfor ikke brukes som dokumentasjon på at slike søknader faktisk er sendt inn til REK.

Bekreftelse på mottatt søknad om godkjenning av forskningsprosjekt (prosjektsøknad) eller generell forskningsbiobank (biobanksøknad) sendes ut fra REK ved registrering av søknader etter utgått søknadsfrist.

De regionale komiteer for medisinsk og helsefaglig forskningsetikk
post@helseforskning.etikkom.no
E-post merkes i emnefeltet med navn på din lokale REK.

From: "post@helseforskning.etikkom.no" <post@helseforskning.etikkom.no>
Date: September 10, 2010 11:17:24 AM GMT+02:00
To: Simon Gilbertson <Simon.Gilbertson@grieg.uib.no>, Simon Gilbertson <Simon.Gilbertson@grieg.uib.no>
Subject: REK vest Musikkterapi som en del av en helhetlig behandling for kolsrammede.

Hei.

Siden prosjektet ønsker å utforske hvordan musikkterapi kan inngå i et utvidet tilbud til KOLS pasienter og brukerperspektivet er i fokus vil ikke prosjektet være fremleggingspliktig for REK. Prosjektet samler ikke helseopplysninger eller har som formål å skaffe tilveie ny kunnskap om sykdom og helse slik helseforskningsloven definerer formålet med prosjekter som skal legges frem.

Prosjektet kan således gjennomføres uten godkjenning fra REK, som ikke har innvendinger mot at resultatene eventuelt blir publisert.

Vennlig hilsen
Anne Berit Kolmannskog
Kontorsjef
REK Vest

Appendix 2: Informed consent

Forespørsel om deltakelse i forskningsprosjektet

”Musikkterapi som en del av en helhetlig behandling av kolsrammede”

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie knyttet opp mot masterstudiet i musikkterapi ved Universitetet i Bergen. Hensikten med studien er å utforske og diskutere, i en fokusgruppe med ulike fagprofesjoner, samt pasientdeltaker, hvordan musikkterapi generelt kan inngå i en helhetlig behandling av kolsrammede. Rent praksis vil dette bety at et utvalg deltakere som alle er tilknyttet Bergen Røde Kors, vil møtes 3 ganger i løpet av høsten 2010 for å sammen diskutere hvordan et eventuelt musikkterapitilbud for kolsrammede bør utformes for å sikre et godt og gjennomtenkt tilbud til denne målgruppen. Studien vil foregå på Bergen Røde Kors sykehjem, parallelt med masterstudentens egenpraksis med kolsrammede og andre med respirasjonsrelaterte sykdommer. Dersom dette er ønskelig, kan observasjoner og erfaringer av hva som foregår i studentens egenpraksis dermed brukes som grunnlag for evaluering og videre diskusjoner i fokusgruppen om musikkterapiens generelle bidrag i helhetlig kolsbehandling.

Fokusgruppen vil bestå av lege, musikkterapeut, sykepleier, hjelpeleier og en pasientdeltaker. Bakgrunnen for utvelgelse av deltakere, er fordi dere alle har viktig kunnskap, enten praktisk, teoretisk eller gjennom selvopplevde erfaringer, om ulike faktorer knyttet opp mot sykdommen kols. Relatert til pasientdeltaker vil også han eller hennes medisinske journal ved Bergen Røde Kors være viktig i forhold til utvelgelse.

For å kunne bygge opp et musikkterapitilbud som inngår i en helhetlig behandling, mener jeg at man er avhengig av nettopp kunnskap fra ulike fagfelt og bruker selv. Et fokus på helhetlig behandling, hvor ulike fagprofesjoner samt bruker selv bidrar til å forme et behandlingstilbud, er også i tråd med politiske føringer i Helse og Omsorgsdepartementets Samhandlingsrapport fra 2008.

Hva innebærer studien?

I utgangspunktet er det ønskelig med tre samlinger for fokusgruppen, med ett tidsrom på 1 time per gang i løpet av høsten og vinteren 2010. Samtaler under samlingene vil bli dokumentert på lydopptak for videre transkribering og analyse av masterstudenten. Samlingene vil foregå på Bergen Røde Kors sykehjem. Tidspunkt for fokusgruppen tenkes utarbeidet i samarbeid med deltakere i den hensikt å tilpasse de til deltakernes arbeids- og institusjonshverdag.

Dersom den forespurte underveis i studien, ikke lenger ønsker å være med , vil en formell dokumentasjon bli gitt til den det måtte gjelde, hvor personens innsats i prosjektet vil bli verdsatt.

Mulige fordeler og ulemper

I forhold til ulemper mener jeg at relatert til pasientdeltakerne, kan dette være blant annet fysiske ulemper som ubehag i pust ,som følge av pågående diskusjoner, samt psykisk stress ved å dele personlige tanker relatert til egen sykdomssituasjon. Det fysiske ubehaget kan forsøkes redusert ved å la deltakeren ta med respirator, mens sistnevnte risiko kan forsøkes redusert gjennom å være respektfull for hva hun eller han deler i gruppen, samt diskutere behovet for konfidensialitet

Relatert til personaldeltakerne, vil den største ulempen muligens være at fokusgruppen blir en ekstra belastning og stressfaktor i arbeidshverdagen .For å redusere dette, vil jeg forsøke å tilpasse tidspunkt og varighet på fokusgruppen etter deres arbeidsrutiner. Denne tilpasningen bør også ta hensyn til pasientdeltakerens hverdag på Bergen Røde Kors.

Ønskelige fordeler ved mitt forskningsprosjekt, er at studien kan bidra til å øke personlige kunnskap som følge av interaksjon med andre fagfelt, samt skape sosiale nettverk som kan påvirke muligheten for tverrfaglig samarbeid på institusjonen i en positiv retning. I forhold til pasientdeltakeren, kan deltakelse også gi han eller henne en sjanse til å bruke sine erfaringer med kols, til å forme sitt eget og forhåpentligvis andre kolsrammedes behandlingstilbud i en positiv retning.

I forhold til vitenskapelig fordeler ønsker jeg at forskningsresultatet, basert på deltakernes kunnskapsutvikling kan bidra som et ledd i utviklingen av ett mer helhetlig behandlingstilbud for kolsrammede, hvor musikkterapi inngår som en del av behandlingen.

Pasienten/studiedeltakeren vil bli orientert så raskt som mulig dersom ny informasjon blir tilgjengelig som kan påvirke pasientens/forsøkspersonens/deltakerens villighet til å delta i studien. Pasienten/studiedeltakeren skal også opplyses om mulige beslutninger/situasjoner som gjør at deres deltagelse i studien kan bli avsluttet tidligere enn planlagt.

Siden studien vil foregå ved Bergen Røde Kors sykehjem vil det ikke være noen ekstra kostnader i forhold til transport og liknende for å delta i studien.

Hva skjer med informasjonen om deg?

Samtalene under fokusgruppeintervjuene vil bli dokumentert på lydopptak og låses inn på trygt sted etter hver samling. Opptakene vil bli transkribert og danner grunnlaget for masterstudentens analysering og drøfting av forskningspørsmålet. Datamaterialet vil analyseres underveis, noe som betyr at studenten ønsker å åpne opp for at deltakere får innsikt i den originale transkripsjonen samt analysen av denne, og kan komme med kommentarer og innspill. Dette for å minske risiko for misrepresentasjoner av deltakernes utsagn.

Informasjonen som registreres skal kun brukes slik som beskrevet i hensikten med studien. Siden deltakerne i denne studien primært uttaler seg som fagperson, vil anonymisering av navn være valgfritt. Dette er et valg som også kan endres underveis. Dersom man velger å være anonym, vil alle opplysningene bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger . En kode vil dermed bli knyttet til deg og til dine opplysninger gjennom en navneliste. Pasientdeltakers navn vil i første omgang anonymiseres med mindre deltaker ønsker noe annet.

Det er kun autorisert personell, knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Autorisert personell er masterstudent selv, samt hennes veileder Simon Gilbertson ved Unviersitetet i Bergen og kontaktperson Solgrunn Knardal ved Bergen Røde Kors sykehjem.

Lydopptakene fra fokusgruppe-samlingene, vil bli slettet ved masterstudentens innlevering av masteroppgaven den 16.mai 2011. Dersom du velger å være anonym vil det, så langt det er mulig ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Sunniva Ulstein Kayser på telefon 97 14 64 38 eller e-mail: sel007@student.uib.no eller faglig ansvarlig Solgunn Knardal: solgunnknardal@brks.no/ 90 07 52 56

Ytterligere informasjon om studien finnes i kapittel *A*

Ytterligere informasjon om personvern og forsikring finnes i kapittel B

Samtykkeerklæring følger etter kapittel B

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltakelse

Kriteriene for deltakelse er at du er tilknyttet Bergen Røde Kors sykehjem, enten gjennom arbeid eller rehabilitering/behandling. Det er også hensiktsmessig for studien, at du har praksiserfaring fra arbeid og/eller fagkunnskap om kolsrammede og/eller pasienter med andre former for respirasjonslidelser.

Bakgrunnsinformasjon om studien

Forskningsprosjektet vil resultere i den avsluttende masteroppgaven for masterstudenten. Studien er dermed tilknyttet masterstudiet i musikkterapi ved Universitetet i Bergen.
Bakgrunnen for studien er masterstudentens ønske om å utvikle et musikkterapitilbud som en del av en helhetlig behandling av kolsrammede. Ønsket er basert på praksiserfaringer samt forskningslitteratur som belyser hvordan musikkterapi kan bidra i forhold til kolsrammede.

Foreløpig tidsskjema (tidspunkt og dager vil bli bestemt i samarbeid med deltakerne i fokusgruppen)

Fredag 3. september 2010: Framleggingsvurdering sendes til REK
Tirsdag 7. september 2010: Masterstudent starter sin egenpraksisperiode ved Bergen Røde Kors sykehjem. Denne egenpraksisen går parallelt med forskningsprosjektet høsten og vinteren 2010-09-01
Uke 40/41: Første fokusgruppeintervju.
Uke 44/45: Andre fokusgruppeintervju
Uke 49/50: Avsluttende fokusgruppeintervju
Vår 2011: Pågående dataanalyse/masteroppgave
16.mai 2011: Prosjektslutt ved innlevering av masteroppgave

Kapittel B - Personvern

Personvern
Opplysninger som registreres om deg er navn samt fagprofesjon og din arbeidsbakgrunn for å delta i studien. For pasientdeltaker vil navn registreres, men anonymiseres, med mindre annet er ønskelig. Bakgrunn for pasientrepresentant sin deltakelse i studien vil også bli registrert via informasjon fra pasient selv, og gjennom informasjon fra pasientens journal ved Bergen Røde Kors.

Utlevering av materiale og opplysninger til andre
Hvis du sier ja til å delta i studien, gir du også ditt samtykke til at opplysninger utleveres til Universitetet i Bergen, Norge for publisering av masteroppgaven. Med mindre annen beskjed er gitt vil opplysningene være avidentifiserte for pasientdeltakers vedkomne og for hver av de andre deltakerne som måtte ønske det.

Rett til innsyn og sletting av opplysninger om deg og sletting av prøver
Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Informasjon om utfallet av studien

Deltakerne i forskningsprosjekt har rett til å få informasjon om utfallet av studien. Denne informasjonen kan for de som ønsker det, bli gitt via en kortfattet og forenklet versjon av masteroppgaven.

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Stedfortredende samtykke når berettiget, enten i tillegg til personen selv eller istedenfor

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(Signert av nærstående, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Appendix 3: Interview guide number 1:

<u>Fokusgruppeintervju på Bergen Røde Kors</u>

Deltakere: hjelpepleier, fysioterapeut, musikkterapeut, lege, pasientrepresentant, sykepleier (?)

Tid: onsdag 27. Oktober kl. 11.00

Åpning:

Hjertelig velkommen til denne fokusgruppe-samlingen som er nummer 1 av totalt 3 samlinger. Først av alt vil jeg si tusen takk for at dere alle er her i dag for å snakke om hvordan musikkterapi kan inngå som en del av en helhetlig behandling av kolsrammede. Alle som er her i dag ble valg på bakgrunn av at deres med erfaringer og kunnskap om ulike faktorer rundt sykdommen kols.

Jeg vil minne om at dette er en frivillig deltakelse og at enhver har rett til å trekke seg om og når de måtte ønske det.

Før vi starter vil jeg opplyse om at vi har en tidsramme på 1 time og jeg vil holde tiden. Dersom noen har behov for å f.eks gå på toalettet, før vi starter, er det anledning til dette nå. Dersom det er noe dere føler behov for underveis, så føl dere fri til å gi meg beskjed.

Dere har alle her mottatt et informert samtykke hvor blant annet graden av konfidensialitet ble beskrevet som valgfritt for profesjonsdeltakerne. For å ikke bruke tid på dette nå, er det fint om dere gir meg en tilbakemelding i etterkant av samlingen om dere ønsker å være anonyme eller ei. For pasient-deltakeren har jeg tatt utgangspunkt i full konfidensialitet, men dette kan endres på dersom du ønsker noe annet. I så fall kan du gi meg beskjed når det måtte passe for deg.

Jeg har med meg opptaksutsyr for å ta opp samtalene. Denne vil transkriberes og danne grunnlaget for dataanalysen. Datamaterialet vil, som jeg skrev i samtykket bli analysert mellom hver samling og dere vil få tilgang til denne analysen. Dette er for å redusere sjansene for at utsagn blir feiltolket. Intensjonene med dataanalysene mellom hvert møte er å forsøke identifisere noen faktorer og retninger som vi kan bruke på den neste møte til å diskutere videre.

Som nevnt innledningsvis er hensikten med disse fokusgruppesamlingen å diskutere og å komme med noen tanker om hvordan dere tror at musikkterapi kan inngå som del av ett helhetlig behandlingsfokus hos kolsrammede. Dette kan diskuteres ut fra ditt ståsted og kunnskap/erfaringsbase og/eller dine mer spesfikke erfaringer med musikkterapi. Med andre ord er deres rolle i gruppen å anse som representanter for deres felt og deres utsagn vil brukes som grunnlag for å konstruere teoretiske konsepter omkring dette temaet. Min egenpraksis ved Bergen Røde Kors er ikke formelt knyttet opp mot dette studiet, men kan trekkes inn i innspill og diskusjoner dersom dere føler at dette er relevant.

Siden det finnes relativt smalt litteraturfelt omkring musikkterapi og kols, er denne gruppen ment som et forum for en bred diskusjon og tankeutveksling omkring teamet. Med andre ord er det ingen riktig eller feile svar og jeg er opptatt av å fange deres erfaringer og kunnskap, både like og ulike erfaringer. Det er viktig at du deler andre deler dine synspunkt selv om de er annerledes enn hva andre sier.

Til slutt vil jeg foreslå noen retningslinjer

- Føl deg fri til å snakke, men det er fint om en person snakker om gang. Siden jeg tar opp dette vil jeg helst unngå å gå glipp av noen av kommentarene. Hvis du har vansker med å høre hva noen sier, så bare si fra
- Min rolle her er å spørre spørsmål,lytte og faslitiere til diskusjon. Jeg vil ikke delta aktivt i samtalen, men være en diskusjonsguide og sørger for at alle får si noe innenfor det gitte tidsrommet. Føl dere fri til å snakke til gruppen og ikke bare direkte til meg.
- Hvis noen av dere skulle komme på ting i etterhånd av samlingen som dere ønsker at skal være med, så er det bare å komme å snakke med meg. Jeg er også tilgjengelig, som det står i samtykket på tlf 97 14 64 38 eller mail: sel007@student.uib.no
- Er det noen spørsmål før vi begynner?

"Warm up"

- Først av alt er det fint om vi tar en runde der vi presenterer oss selv og gjerne sier noen par ord om hva vi tenker om det å være med her i dag. Vi kan begynne her fra høyre

Generelle spørsmål

- Siden dette er en studie som fokuserer på musikkterapien i helhetlig behandling av kols, er det jo naturlig å trekke inn bruk og forhold til musikk. Det hadde derfor vært fint om dere alle kunne si litt om deres musikkbruk/interesser/ erfaringer (vi kan jo begynne fra venstre denne gangen)
- Hvilke type kjennskap, dersom du har det, har du til musikkterapi? Hvor har du i så fall disse erfaringerene/kjennskapen fra?
- Follow up: I relasjon til det forrige spørsmålet, hvilke tanker har du gjort deg opp om musikkterapi? (bidrag, fokus, arbeidsmetoder, samarbeid)

Spesifikke spørsmål:

- Dette er jo en studie som fokuserer på helhetlig behandling. Hvilke tanker har dere knyttet opp mot dette begrepet? Relater det gjerne til egen erfaring (imøtekommelse av ulike faktorer knyttet opp mot sykdom, samarbeid på tvers av profesjoner, brukermedvirkning, kontekstuelle faktorer)

- Hvilke konsekvenser tror dere at dette helhetlige fokuset vil kunne ha i en kolsbehandling? (et snevert behandlingsfokus til nå på tross av forskning som viser at kolssykdommen påvirker flere faktorer i den rammedes liv.)
- Som sagt, er musikkterapi og kols et relativt uutforsket område. Hvorfor tror dere at dette er tilfellet?
- Evt: hvorfor har det kun vært et kvantiativt fokus på dette temaet?
- Men relatert til det dere selv fortalte om musikk og evt hvilke (personlige/profesjonelle) erfaringer/tanker dere har om de å bruke musikk er det noe dere vil trekke frem som relevante i forhold til helhetlig behandling av mennesker med kols? (kreativitet, pust og sangøvelser, livsglede/kvalitet, fokus på noe friskt, gjennopptakelse av gamle hobbyer, brukerstyring)
- Sånn helt mot slutten, er det noen av dere som har noen videre innspill? Som sagt, kan dere kontakte meg i ettterkant også.

"Closure"

- Før vi avslutter har jeg satt av litt tid til å ta en runde og høre om hvordan dere har opplevd å være med i gruppen og eventuelt om det er noe som bør endres på/gjøres klarere til neste gang?

Avslutning:

Igjen takk for at dere tok dere tid til å delta. Dersom dere har gjort dere opp noen personlige meninger omkring anonymisering, er det fint om dere tar kontakt med meg enten i løpet av dagen, eller via mail/telefon. Dette er et valg som kan endres på underveis også.

Neste samling vil bli i uke … på samme plass.Jeg har imidlertid fått tilbakemelding på forhånd om at tidspunket passer dårlig for enkelte faggrupper. **Lurer derfor på om det passer kl. … (sjekk!)neste gang.** Hvis dere ikke vet det enda, er det viktig at dere kontakter meg om hvilke andre dag og tidspunkt dere kan i denne uken, slik at vi kan prøve å få samlingene til å så langt det er mulig, passe inn i deres daglige liv og rutiner.

Jeg ser frem til å treffe dere igjen.

Appendix 4: Interview-guide number 2

INTERVJUGUIDE TIL FOKUSGRUPPEINTERVJU NR. 2 17.NOVEMBER 2010 KL.13.30

Integrering av musikkterapi i kolsbehandling. Begrensninger, krav og kompetanse.

- Er det noen konsekvenser ved det å inkludere musikkterapi i kolsbehandling? I så fall hvilke?
- Hvordan måtte man som musikkterapeut tilpasset seg/ hvilke krav stiller det til musikkterapeuten å jobbe innenfor kolsbehandling?
- Hvilken begrensninger er det i musikkterapi? Hva måtte faget tilegne seg for å kunne integreres i kolsbehandling?
- Er bruk av musikk i møte med kolsrammede forbehold musikkterapeuter?
- Kan andre profesjoner også kan ta i bruk musikk? Hvordan?
- Fordeler og ulemper?
- Forrige gang snakket doktoren om hvordan vi i et helhetlig syn ser på mennesket i forhold til deres fysiske, psykologiske, sprituelle, essensielle og sosiale fakorer. Hvordan tenker dere at musikkterapeuten bør jobbe for å imøtekomme disse faktoerene? Er det andre faktorer i tillegg?
- Spørre direkte til pasient først, deretter til de andre: Kan musikkterapi ha noe for seg også hos kolspasienter som ikke har den musikalske bakgrunnen kolsrperesentaten her i gruppen har? I så fall hvordan?
- Forrige snakket dere en del om at kols er en pasientgruppe som har vært underprioritert? Hva ligger bak denne underprioriteringen (krefter i samfunnet, medisinske miljøer, bruker selv?) Hvilke konsekvenser får underprioriteringen for gruppen?
- Hva må til for å øke prioriteringen?

Tverrfaglig samarbeid

- Hvordan tror dere ett tverrfaglig samarbeid mellom dere og musikkterapeuten og brukeren kunne sett ut?
- Er det noen av deres allerede etablerte behandlingstilbud/intervensjoner som dere kan tenke dere at musikkterapi kunne inngått i?
- På bakgrunn av sist gang, så ser det ut til at ordet helhetlig brukes på tre måter: både det å se hele mennesket, det å jobbe sammen og lære av hverandre profesjoner og det å lytte til pasienten og la han eller hun med sine interesser påvirke behandlingen. Hvordan bør musikkterapien utvikles for å være med å imøtekomme dette?
- Hvordan tenker du som representant for mennesker med kols, at et slikt opplegg skulle vært?

Direkte spørsmål:

Til pasient

- Hvordan kan du bruke korerfaringene i musikkterapi?
- Forrige gang sa du at du synes det gjør godt å synge? Kan du utdype litt mer på hvilken måte du føler at det gjør godt å synge
- Sist gang sa du at du synes det er gøy å få være med på dette her, kan du uttype dette litt nærmere? (Brukerstyring)
- Sist så sa du at du synes det å bruke munnspill var greit og okay. Kunne du kanskje fortalt litt mer om hvordan du opplever dette?
- Tror du at også andre personer med kols som ikke har den musikalske bakgrunnen du har, kunne hatt nytte av musikkterapi. I så fall hvorfor?

Til doktor

- Forrige gang sa du at musikk kunne brukes til å trene lungefunksjonen. Kan du uttype litt nærmere på hvilken måte musikk kan brukes for å trene lungefunksjonen?

Oppfølgingsspørsmål til alle:

- Forrige gang snakket dere en del om at musikk kunne brukes litt som avledning og motivator i trening, at man får trening indirekte inn, som du fysioterapeut nevnte og at det blir en glede ut av det. Kan disse faktorene påvirke effekten av musikkterapi i møte med kolsrammede? I så fall hvordan?

Til hjelpepleier:

- Forrige gang sa du at du hadde sett positive effekter av musikkterapien med kolsrepresentaten. På hvilke måte ser du dette og hva tror du kan være årsaken til denne effekten?

Appendix 5: Interview-guide number 3

Intervjuguide fokusgruppe 3: 9/12 10 kl.13.15-14.15

"Warm-up":

Synge en julesang – tenk over hvordan dere bruker pusten i denne sangen. Fortell litt om det etterpå.

Musikkterapeutisk etablering:

Hvordan kan mt nyttiggjøre seg av den medisinsk kunnskap i sitt opplegg?
Hvilke "kvaliteter" i mt mener det er viktig å legge vekt på for at faget skal integreres i kolsbehandling.

Musikk og motivasjon

Hvordan skaper musikk motivasjon?
Hvordan kan denne motivasjonen påvirke prosess og resultat?

Prioritering

Hvilken rolle kan mt ha i denne prioriteringsprosessen

Sykdomsbilde

Hvordan kan mt bidra innnenfor den sammensatte problematikken?
Hvilke utfordringer i behandlingen møter man når sykdommen er kronisk? Hvilke utfordringer møter brukeren?

Dialog

Hvilken ressurser har man for å muliggjøre dialog?
Er det noen som ikke er her, som dere mener er viktig å ha med i denne dialogen?

Musikkterapi i gruppesammenheng

Hvordan kan mt bidra i gruppesammenheng?

Kolsrepresentant:

Uttyp mestringsopplevelsen og motivasjonen. Motivasjon: relatert til at han sa seg enig med fysioterapeut i at det er noe du blir glad av. Spør om det er relasjon mellom den gleden og den motivasjonen han opplever.

Utdyp hvordan han kan ta i bruk musikk ellers i hverdagen?

Helhetlig tankegang

Kan musikkterapi passe inn i en helhetlig tankegang? I så fall hvordan?